1-1-2012

Reality or rhetoric? Community involvement in primary care in north inner city Dublin.

Fiona O'Reilly
Royal College of Surgeons in Ireland

Reality or Rhetoric? Community Involvement in Primary Care in North Inner City Dublin

Fiona O'Reilly RGN RSCN MSc Community Health

University address: 123 St Stephens Green, Dublin 2, Ireland

Member: Royal College of Surgeons in Ireland

Submitted to: Department of General Practice, Royal College of Surgeons in Ireland

Qualification: PhD Higher Degree

Date submitted: November 2012

Supervisor: Professor David L Whitford, MD (Cantab), MA, MB BS, FRCGP, DRCOG

Declaration

I declare that this thesis, which I submit to RCSI for examination in consideration of the award of a higher degree PhD is my own personal effort. Where any of the content presented is the result of input or data from a related collaborative research programme this is duly acknowledged in the text such that it is possible to ascertain how much of the work is my own. I have not already obtained a degree in RCSI or elsewhere on the basis of this work. Furthermore, I took reasonable care to ensure that the work is original, and, to the best of my knowledge, does not breach copyright law, and has not been taken from other sources except where such work has been cited and acknowledged within the text.

Signed _____

RCSI Student Number _____

Date _____

Acknowledgements

This felt like such a lonely path, I thought at the end I would have no one to thank or blame but myself. On reflection this is not true and now as I get closer to the end I can feel more than my own relief. I thank my Mother, family and friends for their support, patience and understanding. In particular I thank my children Kern and Ena and my partner Stephen.

I sincerely wish to thank my supervisor Professor David Whitford, for his continuous support and advice but most of all for not giving up on me. I thank Dr Austin O' Carroll for his undying enthusiasm and interest and for reading and commenting on drafts. Thanks to Dr Jamie Saris for introducing me to anthropology and a different way of thinking about the world.

I thank Liam Quinn whose positive encouragement came just at the right time. Besides a wave of the hand and utterances of "carry on" and, "you're nearly there", he painstakingly proof read the thing. I am also sincerely grateful to my friends Derek Lee and Mary Corbett who helped with more proof reading at the eleventh hour.

I am grateful to Emily Reaper and Christy Flood who provided access to another world where the stigma of drug use defines lives. I thank Christy for his insights and Emily for her friendship. Christy sadly passed away in 2008.

Most of all I thank my Dad who inspired me to be all that I could, and then some.

This was a lonely path because you were not able to help me this time, like you have so many times before. While you faded away you never stopped encouraging me to finish. I am sorry you did not last to see the final product. When you could hardly speak you would ask, "Is the thesis done yet?" I lied then. I do not lie now –

The thesis is done!

For Dad

TABLES

FIGURES

APPENDICES

Summary

Irish Primary Care policy sees community involvement as a principle to guide the development of services. This study explores how the policy arena was reflected in the lived reality of community and Primary Care in north inner city Dublin. Meaning of community involvement in health is explored through an analysis of the evolution of the construct. The policy arena is described particularly in relation to the Irish context. Against this backdrop spatial practice and power relations are described and analysed to understand what community involvement in Primary Care means in the context of Dublin's north inner city.

An ethnographic approach was used, involving participant observation in different social settings. These included the community sector, a Primary Care Partnership and an action research project with drug service users. Cornwall and colleagues' conceptualisation of spaces for participation is used to describe and analyse these spaces in order to identify influence on decision-making in Primary Care.

In contrast to the aims of national policy this study finds that communities did not influence formal Primary Care planning or decision making in the study area. It finds barriers to the involvement of community voice in Primary Care planning and development and concludes that these barriers are even greater for the socially marginalised group - drug users. Barriers to local influence (including influence by GPs), included top down decision making, covert health service planning, fear of confrontation, a historical lack of health service development and the lack of an identifiable 'system' of Primary Care. Barriers to involvement from the community side included the prioritisation of more critical issues for community action. Health status and services were not considered as targets for community action. GP were not involved in community agendas nor were they seen, either by themselves or the community, as relevant to them.

In practice community action through the formalised community sector addressed the underlying social determinants of health. Primary Care (as framed in policy) places community actions outside the frame. The design of the system and structure of Primary Care is being

played out away from the public arena, and without inclusion of frontline Primary Care providers.

If community is to be involved in a meaningful way it will be necessary for Primary Care to be reframed to include efforts to tackle the underlying social determinants of health. This would therefor include the range of actions, projects, and services important to communities at least in deprived areas. I suggest that without such reframing, the aim should be to democratise decision making in spaces where decisions occur rather than supporting broad development ideologies which become meaningless in practice. I argue that the spatial conceptualisation of participative practice is useful for identifying opportunities to democratise decision making.

Preface

Mary is a Public Health Nurse (PHN), her 'patch' is a deprived area of the north inner city. Unlike GPs who work from a patient lists, PHNs are assigned to areas. Street by street the area is divided up and covered by PHNs working from local health centres. I shadowed Mary as she visited people in their own homes.

The first call is to a local authority house close to the health centre. We enter on the ground floor, stairs immediately brings us down to another level, it is very dark, very steep. We go into a very neat and tidy kitchen. There is a woman standing in her nightdress, looking for her lighter, she wants a cigarette and pays little attention to us. Mary takes out the needle; the woman pulls up her nightdress displaying her underwear, and grabs hold of her stomach towards Mary who jabs her with the needle. Mary asks her how she is and checks her blood sugar. A bit of chit chat and we are gone. Mary starts off her day this way every morning.

Throughout the day we leave the health centre, meander through the streets I had come to avoid as dangerous no go areas in my home city. Though the area had changed it was still an area where non-residents would not stray without good reason. Mary assures me however, that she has never come to any harm on these streets. She believes it is because everyone knows her as *the nurse*.

The next call is to visit an elderly man in a long term residential residence for homeless people, to dress his leg ulcer. The first person we meet in the home is the project worker who lives locally. As we enter her son drops in to kiss his mam goodbye before he goes to school. The woman speaks to Mary at length about how brilliant her son is doing now that he is on Ritalin. It appears that Mary had referred him to a specialist and as a result he was prescribed Ritalin. "He's like a changed boy", his mother was delighted. "He takes pride in his schoolwork and brings his report home and is really, really doing well". "He goes to the after schools project and loves it" she reports.

Later in the day as we walk through a well-known drug dealing area, a woman sitting on the wall of a garden in front of the terraced houses calls out to Mary. The woman, in her early forties holds her six month old grandson. She asks Mary for advice on which type of hearing aid she should get for her daughter. "They're talking about the ones on the inside" she says and asked Mary what she thinks. Mary knows the daughter, Ciara, 4 years old, now playing around the corner. Mary had just seen her on her scooter and tells the women that the child

was "doing great" and that, "her language is coming on great". The woman is not sure about letting her have an operation. Mary advised her to have the child assessed fully and to "see what they say". As we leave the woman mentions that she was on her way to visit her nephew in Beaumont (Hospital) who had been shot the previous night. Mary asks about her son, Daniel, and her other daughter. (Field notes: January 2006)

The nurse did her work in people's homes and along the streets in the local area where they lived. She also visited schools, day care for elderly, a reception centre for asylum seekers as well as the long term care centre for the homeless. Mary did dressings, examined new babies, gave advice, listened and laughed. Many times along the way Mary was stopped in the streets by people to talk or for her advice on something. It was difficult to count how many 'patients' she saw as it was difficult to identify people as patients.

After the early morning visit to the hostel for homeless people the GP cycled back to his practice 10 minutes away. The practice was busy, he immediately began seeing patients. Patients were clearly identified as 'patients', they were separated from natural habitat and others and seen in a special (consultation) room. The GP had 10 minutes in which to diagnose the problem or disease. I sat in the consultation room and observed;

The doctor sits on a swivel chair at the desk facing the window, with a computer on top. The patient sits on the same side of the desk as the doctor with the chair facing the doctor. The doctor turns from patient to computer to patient intermittently using stethoscope, auriscope and sphygmomanometer on the patient and typing on the computer. He greets patients by shaking hands, he calls them by name. The patient's file is opened on the computer as soon as they enter. They are respectful, some call him by his first name others (older patients) call him 'doctor'. Consultations last approximately 10 minutes. There is often something else going on at some point of the consultation e.g. the receptionist phones or knocks to ask something or the doctor makes or takes a phone call. I was aware of the speed, the movement and the need not to waste time. The consultation ends with the GP giving the patient a prescription (Field Notes: February 2006).

The GP sees and treats patients alone. On occasion he sends someone into the practice nurse or consults with her for results. For some patients he calls the liaison nurse in the Hospital to have notes checked or consults with a hospital doctor or psychiatrist.

Chapter 1 Introduction

The above are all examples of 'primary care' in modern-day Ireland. Primary care, however, is a relatively new term in Irish medical practice. Previously health care professionals who worked outside hospital settings in the community worked under various labels such as 'community services', 'family medicine' or 'general practice' and 'community pharmacies' to name but a few. The first Primary Care strategy (Department of Health and Children 2001a) saw these, often disparate groupings under the one banner and as part of the same system (2001). This inaugural strategy took a broad view of Primary Care as an approach to health care provided by a wide range of health professionals working in teams in the community and with emphasis on involving communities (Department of Health and Children 2001a).

Through the evolving vision of what Primary Care is and should be in Ireland has come a strengthening commitment to involving communities in Primary Care planning and delivery. The Primary Care Strategy along with the national health strategy aims to place the patient at the centre of the system. The strategies aim to ensure the patient is at the centre of the care delivery system and are committed to the principles of involvement of community in decisions about health service delivery (Department of Health and Children 2001b). Subsequent national policies endorse and further commit to the involvement of service users, community sector and local communities (Department of Health and Children 2006;Department of Health and Children and HSE 2008;Health Services Executive 2010). In 2007 as a consequence of the 2004 Health Act a national complaints system was launched (Department of Health and Children and HSE 2008). All of these policy commitments promote community involvement in Primary Care as an obvious social goal. The most specific articulation is found in action 19 of the Primary Care Strategy (2001). This commits to the establishment of active community involvement in Primary Care teams.

Such documents and others suggest that politics and health care are intertwined in modern Ireland. Of course, such entanglements are nothing new: the notion of participation in health can be traced to the colonial and post-independence era in developing countries where less expensive models of health care had to be established if newly independent countries were to be able manage them (Hickey and Mohan 2004). There is wide recognition that the crystallisation of ideas about community involvement in health concurred with the formalisation of the Primary Health Care (PHC) movement (Jewkes and Murcott

1998;Macdonald 1992;Starfield 1992;WHO and UNICEF 1978). The UNICEF/WHO conference at Alma Ata in 1978 was a watershed in the development of these ideas which were seen as an integral part of the provision of accessible, affordable and appropriate health care (Navarro 2002;World Health Organisation 1970)

The Primary Health Care (PHC) model in developing countries aimed to bring services where there were none. Community participation was a core element which would enable this extension, through basic training task-sharing, and volunteerism. In developed countries such services existed without lay involvement (Prickard and Smith 2001). There were however other influences leading to an emphasis on peoples participation in health. The citizen rights movement was influential particularly in the USA which promoted an emphasis on the development of patient rights. Concern about the growing costs of health care has also led to creeping market models into the provision of care, especially with increased focus on evaluation outcomes and consumer satisfaction (Delaney, Keegan, and McGee 2002).

The motivations for participation in health range from the ideological which see it as an end in itself and follow the community development approach (Chambers 1997a;Freire 1970;WHO and UNICEF 1978) to participation as a means to maintain or bolster traditional decision making processes (Coulter and Ellins 2006;harrison and Mort 1998;Harrison and Mort 1998;Rowe and Shepherd 2002). Coulter (2006) describes the potential benefits to the Service (e.g. improved public confidence); to people (e.g. more responsive services); to public health (e.g. improved health); and to society as whole (e.g. building social capital) as a result of participation in health services decision making. The differentiation is made between the democratic approach which is strongly associated with public empowerment and active citizenship and the consumerist approach which is about responsiveness and choice. Community involvement is thought to challenge the traditional concept of professional control and power emphasising the valuing of citizen's knowledge and practice (Brown 1994a;Jewkes and Murcott 1998).

How Primary Health Care and Primary Care are conceptualised is pertinent to this study. Though used interchangeably by some there are important conceptual distinctions based on interpretations (in PHC) of health as a reflection of socio-economic determinants (Bhatia and Rifkin 2010). Theoretical distinctions and the development of both concepts are described in

chapter two (pages 35-41). However both Primary Health Care and Primary Care overlap in their aim to prevent and treat the simplest ailments for the majority of the population. Primary Medical Care is seen as a component of Primary care and generally refers to services provided by GPs.

The Irish health service

The Irish health care system is drawn from a number of models to become the current 'mixed ' system of health service funding and provisions (Layte and Nolan 2004) . It is predominantly a tax funded system and with OECD estimates indicating total health spending per capita at 101.8% of the EU per capita average, in 2002. Most services are run on a cost sharing basis; user fees are higher than in other countries particularly in Primary Care (Smith 2010b). Nevertheless general medical services (GMS) are free to the poorest third of the population (category 1) who are entitled to a medical card. Free GMS included the elderly (over 70 years) until this entitlement was removed in 2009 when a means test was introduced (Tussing and Wren 2006;Wiley 2005). In 2005 a new 'GP (family doctor) Visit' medical card was introduced and has been granted to only 2% of the population (Smith 2010b). Non-medical card holders (category 2) have limited eligibility to a range of services. The services of the General Practitioner must be paid for (approximately €45-€60 per visit) by this, approximately two thirds of the population 'out of pocket' (Smith 2010a;Smith 2010b;Wiley 2005). Public coverage for other Primary Care services provided largely by private practitioners i.e. dental, ophthalmic, and aural services is restricted mainly to Category I individuals (excluding GP Visit card holders). Health economist rarely specify costs of non-private Primary Care providers which they differentiate as 'community care services' (Smith 2010b). Community services in this context include public health nursing, home help services, physiotherapy, chiropody, occupational therapy etc. These services are free at the point of use. The Irish system contrasts to that of the UK where most health care in the NHS covers all the population and is free at the point of use (Smith 2010b).

Structure of the health system

The Department of Health was established in 1947 and in 1997 became the Department of Health and Children (DOHC). It assumed overall responsibility for the development of health policy and for planning the health services (McCormack 2006). The 1947 act, established the

city or county council as the health authority in each local area (Government of Ireland 1970). At that time the healthcare system of Ireland was largely a private and voluntary system with the Catholic Church retaining effective control of healthcare, in particular the ownership of hospitals and institutions. General Practitioners were sole traders with the state taking few responsibilities beyond the organization of the provision of healthcare to the disadvantaged (Brown 1986).The 1970 Health Act established the Health Board system initially with eight Health Boards. In 1999 the Eastern Regional health authority was introduced and dissolved the Eastern Health Board and created four bodies in its place, thus bringing to eleven the number of regional health authorities (Government of Ireland 1999). In 2005 The Health Service Executive (HSE), replaced the Health Board system following the enactment of the Health Act 2004 becoming the single body responsible for managing and implementing health and personal social services. It is accountable to the DOHC for the implementation of policy, as developed by the Department, and for providing expertise and an evidence-base to the Department in the formulation of public health policy (McCormack 2006).

Evolving ideas of Primary Care

Up until the end of the nineties there is little reference to Primary Care in health policy documentation. 'Community Services' and 'General Practice' described what is now referred to as Primary Care (Eastern Health Board 1980a;Eastern Health Board 1980b;Eastern Health Board 1998). The Community Care programme provided by area Health Boards included a range of services including community nursing, social work, occupational services, supplementary financial welfare services, and welfare services provided in cooperation with voluntary organisations such as services for elderly, disabled, residential care services, day care and clubs (Eastern Health Board 1980). As such community care was seen in broad terms which included family and community;

> complementary working of statutory and voluntary agencies meeting people's needs locally, using the capabilities of the family, the professionals, organised volunteers and the good neighbours as a team'(Eastern Health Board 1980).

There was little integration between Health Board staff and General Practice (Department of Health 1994). In 1993 the GP unit was established in the EHB under the community service programme to help strengthen general practice and integrate services (Eastern Health Board 1998). While the first national health strategy mentions Primary Care briefly, describing

'general practitioner, Public Health Nurse, home help among others' as Primary Care professionals, it was not until the close of the millennium that strategies for Primary Care under that term began to be developed (Department of Health 1994;Eastern Health Board 1999)

The first Primary Care strategy was devised by the Eastern Health Board in 1999 followed a year later by a the Western Health Board's (WHB) strategy (Eastern Health Board 1999;Western Health Board 2000). These documents quoted the WHO definition of Primary Health Care:

> Primary Health Care is the first level of contact of individuals, the family and the community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process. (World Health Organisation 1978)

There was differing emphasis by different health boards on what services comprised Primary Care. In 2001 the national Primary Care strategy clearly defined Primary Care as an approach to care which included a much broader range of services to keep people well:

> *Primary Care is an approach to care that includes a range of services designed to keep people well, from promotion of health and screening for disease to assessment, diagnosis, treatment and rehabilitation as well as personal social services. The services provide first-level contact that is fully accessible by self-referral and have a strong emphasis on working with communities and individuals to improve their health and social well-being(Department of Health and Children 2001a).*

The Strategy refers to services provided by the health professionals in the community whether self-employed or health authority staff, as Primary Care. The composition of the Primary Care Team (PCT) was seen as general practitioners, nurses, midwives, health care assistants, home helps, occupational therapists, physiotherapists, social workers, administrator, receptionist /clerical officers. The Primary Care network which would cover a number of PCTs included Chiropodist, Community Pharmacist, Community Welfare Officer, Dentist, Dietician, Psychologist, Speech and language therapist. Composition could be influenced by a needs

analysis (Department of Health and Children 2001b;Department of Health and Children 2004a). This view of Primary Care broadened out the EHB view but omitted the voluntary sector included in the WHB interpretation.

On the whole, health commentators tend, to take a narrower view of Primary Care considering GPs as the bedrock of primary care and others including the Public Health Nurse (PHN) and allied professionals who are part of Community Services (Smith 2010b;Tussing and Wren 2006). It is generally the view of GPs too that they are the main stay of Primary care as can be seen through the Vision document (ICGP & IMO 2001)and indeed through the natural history of this study (page 91). Primary Care Units were established by regional health authorities to create links with service provided by private contractors (ophthalmic, pharmacy and dental service) giving the impression perhaps that that Primary Care was limited to these services (Northern Area Health Board (NAHB) 2005). On Primary Care team composition, all agree that GPs and PHNs are core members (Boerma 2006;Department of Health and Children 2001;ICGP & IMO 2001;Tussing and Wren 2006). As seen in the preface these disciplines provide generalist services in the community in very different manners to different populations.

While the 2001 Primary Care strategy defined Primary Care and Primary Care Team composition from its perspective, GPs had a different view. Similar to the earlier Eastern Health Board view 'A Vision of General Practice' by the Irish College of General Practice (ICGP) and the Irish Medical Organisation (IMO) saw the 'core generalist team' as consisting of the General Practitioner, the Practice Nurse, the Public Health Nurse, and possibly the Community Pharmacist. It also showed a critical difference in perspective when it stated that 'teamwork requires that team members serve a common patient list' (ICGP & IMO 2001). A fundamental difference and difficulty for team work was the fact that the Health Board staff serviced catchments or areas while the GPs served 'lists'. GPs and PHNs, core team members would not necessarily serve the same populations.

General practice occupies a key position in the Irish health care system. For most patients their general practitioner (GP) is their first 'point of first contact' with the health system. Most illness diagnosis prescription writing and certification of benefits associated with illness is done in general practice (Boland 1997). GPs are self-employed and are paid on a fee-for service basis

for services delivered to private patients. A General Medical Services contract between the health authority and participating GPs was agreed in 1989 based on a capitation system of payment (Boland 1997). Although covering only 30% of the population, the GMS scheme accounts for 57% of GP income and is much valued by GPs as it is superannuated and attracts subsidies for staffing (Teljeur et al. 2010). As a result nearly all general practices in Ireland combine GMS and private practice. From 1999 to 2008 the coverage of the GMS scheme has varied between 28.1% and 32.5% of the population. Consequently most of the population pay full fees to access GPs. An estimated 96% of practices provide care under the GMS scheme (Teljeur etal. 2010).

In the early days of the GMS contract (for the provision of services to medical card holders) the supply of GPs out- weighed demand, however today though the number has increased, there are inadequate numbers of GPs s (Tussing and Wren 2006). In 2002 Ireland reported 0.6 GPs per 1000 population, this was the same as UK however compared poorly to other European countries e.g. France Germany Belgium Norway all of whom had more than 1 GP per 1000 population (Saltman, Rico, and Boerma 2006). The distribution of GPs in Ireland is relatively equitable although the most deprived practices have high workloads or appear to be overstretched (Teljeur et al 2010).

Problems with the system

The problems with the Primary Care system are outlined in the Primary Care Strategy document and inferred in the Vision paper (Department of Health and Children 2001a;ICGP & IMO 2001). The system was fragmented and difficult to access out of hours. The emphasis was on diagnosis and treatment rather than prevention promotion and rehabilitation. There were poor links between primary and secondary services and medical services predominated with scarcity of other elements e.g. social services occupational therapy physiotherapy counselling home help. GPs worked in isolation poor integration with other services (Department of Health and Children 2001a;Tussing and Wren 2006)

The GPs through the Vision document called for incentives for the development of group practices offering more services; computerisation, infrastructure staffing and equipment etc. and a different approach to teamwork. They wanted universal patient registration with a GP

whereas Primary Care Strategy wanted voluntary registration with a team. There were differences seen in perspectives on the make-up of teams too (ICGP & IMO 2001;Tussing and Wren 2006). In short the GP vision saw GPs as more central to Primary Care than did the Primary Care Strategy where the emphasis was multidisciplinary teams providing a broad range of services. The Vision document make a distinction between Primary Care and Community Care suggesting the conceptual basis of the strategy is not accepted by those representing GPs.

Health Reforms and the democratic process

Since the 2001 health strategy there has been increased policy development committing to the principle of involvement. At the same time restructuring favoured over democratic representation on Health Boards (Watson Wyatt Worldwide 2003). Furthermore the health system has moved towards a centralised model which presents challenges for locally based community involvement. In 2005 the 10 autonomous regional Health Boards (and Eastern Region health authority) were abolished to make way for the establishment of the Health Service Executive (Government of Ireland 2004a). Up until this the Health Boards made up of elected representatives (more than half), professional representatives and nominees from the Minister, had statutory responsibility for the health services (O'Hara 1998).

The Health Board model allowed the interests of individuals and communities be reflected through the participation of elected local representatives in the governance of Health Boards, and the health authorities (Watson Wyatt Worldwide 2003). Though the Brennan Report (Department of Health and Children 2003a) which also recommended the establishment of an 'Executive' to manage the Irish health service as a unitary national service was in favour of keeping, albeit rationalising, the 'Board' as a 'democratic model' ,it was ignored and the Health Boards were abolished (Department of Health and Children 2003b). The media noted too at the time that, 'this would considerably reduce the influence of local representatives '(2003 RTE).

The 'need to consolidate fragmented structures and functions to enable the health system deliver sustained value for money and a high quality of service for consumers' was given priority over the need to maintain a democratic model which aimed to reflect communities interests. Indeed there is some suggestion that the two aims may be in conflict. The

Prospectus report noted several problems arising from this which are relevant to community involvement in health care decision making. It noted that in an attempt to respond to local consumer and political involvement 'a number of structures and functions have been duplicated or executed in different ways'. This, the report says can risk value for money and quality of care interests (Watson Wyatt Worldwide 2003).

Though the system wide view was prioritised over the local view, nevertheless successive policy documents further commits to principles of community participation and involvement. As with conceptual variation on Primary Care these conceptual incongruence are not confronted.

The research question

Fetterman (1998) describes the research problem as "what the ethnographer wants to know". I wanted to know how close to reality the national position on people's involvement in health care provision this position was. If a distance between the plan and what I saw existed, I also wanted to understand why this was so. I did not want to limit the definition of Primary Care to one or other interpretations but rather to explore these through examining what actually went on under varying interpretations of this banner. I wanted to see where and how community was involved and what barriers existed to such involvement.

To do this I would need to understand the health system in the north inner city, how it was shaped and who was involved in shaping it. I was interested in the ideologies that aimed and claimed to involve community in health systems. I wanted to know if these ideologies offered a way for people in north inner city Dublin to have a say in health service planning and development. Were people living in deprivation in inner city Dublin actually influential in health care development? If so, to what effect? If not, why not? Would it be feasible and beneficial to them or the system to be involved? Was the health system interested in involving communities? What did it do to facilitate this? In short I wanted to unravel the reality of community involvement in health service planning and decision making in a specific geographic location. I used an ethnographic approach (chapter 3) to gain a greater understanding of the problem I was interested in.

The field for my study was the patch of the north inner city which was defined as the catchment of the North Inner City Partnership in Primary Care. Within this geographic area which spanned three to four miles I carved out three ethnographic sites which I hoped would allow me interrogate my research question comprehensively (see chapter 3).

These were,

1. The North Inner City Partnership in Primary Care :A partnership between the health authority and the GPs working in the area
2. Community Groups in the north inner city: An umbrella network of organisations working in the inner city
3. Marginal Voice: A nested advocacy case study. This action research case study aimed to influence change in the health services according to the views of the drugs service users.

The findings from the above are presented in three data chapters (7,8 &9). At the end of each the analytical frame which merges an analysis of power with an analysis of spaces for participation is applied to interpret results. This framework draws on the work of the Institute of Development Studies group on Participation as well as Foucault and Lukes (Cornwall 2002;Cornwall 2004;Foucault 2000;Gaventa 2002;Lukes 1974;Rainbow 1984). A third stage analysis is employed to aid mid-level explanatory theory building: deconstruction points to the contradictions beneath notions of community involvement in primary care given the lived context and the ways in which Primary Care is currently framed.

The development of a theoretical frame

Because findings and theories used to interpret them are interdependent I cannot describe the frame I used to aid with interpretation without giving away some of the findings which influenced the development of the frame. Analyses influence the selection of theory which influences production of further findings and their interpretation. This iterative process is expanded upon in Chapter 3.

Theory provides a way to link case studies with larger issues. Analysis can link up with theory or lean on it for an interpretive framework (Wolcott 1990). Frameworks themselves can be developed by coming up with new concepts which explain findings or blending different

theories in a new way. The framework developed in this study blended two sets of theory. The first can be generally described as theories about power and the second, theories about participation as spatial practice. The development of this framework which was used in each site to interpret social practice is described below.

In early analysis, as Hammersley and Atkinson put it, I gained familiarity with the data and used it to 'think with'. Interesting patterns were identified and concepts emerged which provided focus for further data collection (Hammersley and Atkinson 1983). An example from this study is the concept of 'divisions' which were observable in different sites. This finding was linked to Foucault's theory on divisions which further informed focus and analysis. This concept prompted further explorations of theories about power.

Divisions applied to person/s place and even to words and meaning was an early and recurring theme emerging from analysis. The description of wandering through the streets with the Public Health Nurse (PHN) and sitting in the consultation room with the GP, for example, presented as the preface prompted me to think about how people became constructed as patients for the doctor but not the nurse and particularly with my research question in mind, how and why community disappeared in the face of medicine. I observed "It was difficult to count how many 'patients' she (the PHN) saw as it was difficult to identify people as patients. It was difficult for me to ascertain their diagnoses." In the GP's consultation room identified as 'patients', people present separated from natural habitat and others examined by expert to isolate the disease or problem from the person. These separations and positions are in keeping with Foucault's "medical gaze" which denotes the way the patient's body was separated from the patient's person and agency – the body emerging as the site of medicine, whose eloquence is purchased by the bearer's silence (Foucault 1973). This view is consistent with MacDonald's analogy of the body as a machine and the doctor as medical scientist or engineer. The engineering approach as opposed to the Primary Health Care approach he says is responsible for separations (divisions). The disease is viewed as separable from body or community and the patient & community is removed from any position of control.

One of the greatest drawbacks of the medical culture that has grown up with the engineering model is the removal of the patient or community from any situation of control in the encounter with the medical profession. Disease tends to be seen by the professional and lay

person alike, as something 'objective', somehow in the individual or in the community, but separable from them, waiting to be identified and dealt with by the medical profession (MacDonald 1994).

Divisions evident in how groups of people were categorised viewed and treated for example how drug users are divided from society physically and socially (chapter 8). Foucault terms 'dividing practices' as modes of manipulation that combine the mediation of a science and the practice of exclusion usually spatial but always social (Rainbow, 1984). Many examples of this including isolation of lepers in the Middle Ages, confinement of the poor and insane and the classification of disease. These dividing practices focus on how the individual is 'objectified' from an undifferentiated mass or from more highly pre-selected populations (delinquents from working class quarters). The individual is objectified by a process of division either within himself or from others. Foucault sees the dividing practices as techniques of domination that have mainly been applied to 'vagabond populations, the working classes those defined as marginal etc. (Rainbow 1984).

Divisions were also implicit in varying perspective of Primary Care definition and meaning. I saw division as implicit to the contrasting principles evident in the conceptual development of the health system specifically Primary Care. Surprisingly though it is used by all as though implicit meaning is identical. For closeness between what is intended and understood, clear divisions between related labels are necessary for example between Primary Care, Primary Health Care, Primary Medical Care, and Community Care and so on. Definition makes division between what it is and what it is not explicit. I was interested in exploring the meaning of these concepts both from a theoretical point of view and implied meaning through lived reality.

Another form of divisions or dividing practices evident from the emerging data was the flurry of area based divisions according to units of administration, funding for anti-poverty initiatives, social inclusion, disease and services among various authorities. Indeed I became preoccupied by this practice to the extent that I would not rest till I had my geographic site of study divided into neat manageable units making legible health inequalities (the results of this can be seen in chapter 5). Literature on the role of social determinant of health and health inequalities helped to construct the field as I chose to explore community action in deprived areas (pages 35-37).

Participation as spatial practice

While the concepts of and theories about divisions were one influence underpinning the frame I used to interpret findings space was the other. Space and division are closely related. Inherent in the idea of space is the imagery of 'boundary'. Gaventa and Cornwall show how power relations help define boundaries of participatory space (Gaventa 2006). Theorists offer a perspective on politics of participation which emphasise the interplay of power and difference in the making of spaces and the interactions within them (Cornwall 2002). Lefebvre (1991) puts forward notions of social spaces as produced spaces which are the outcome of past actions and which enable new actions. In the contexts of citizen action and participation Gavanta (2006) defines spaces as:

> Spaces are opportunities, moments and channels where citizens can act to potentially affect policies, discourses, decisions and relationships that affect their lives and interests (Gaventa 2006)

Cornwall (2004) identifies the concept of 'space' in contemporary development discourse where there is reference to 'opening up', 'widening', 'extending' opportunities for citizens to participate in decision making thereby deepening the democratic process. She notes that 'talk of arena' conveys ideas of spaces where voices jostle for attention (Cornwall 2004). Gaventa (2004), suggests that one dynamic to explore while examining spaces for participation is to ask how they were created, in whose interests and with what terms of engagement (Gaventa 2004). A continuum of spaces has been described which include- closed spaces, invited spaces and claimed/ created spaces. Gaventa points out that these spaces exist in dynamic relationship to one another and are constantly opening and closing through struggles for legitimacy and resistance, co-optation and transformation (Brock, Cornwall, and Gaventa 2001;Cornwall 2002;Cornwall 2004).

Closed spaces are those which do not allow participation by excluding certain stakeholders these may seek legitimacy by creating invited spaces. Here decisions are made behind closed doors with-out any pretence of broadening the boundaries for inclusion (Gaventa 2006).

Invited spaces often occur as efforts are made to widen participation. Previously closed spaces can move to invited spaces as 'authorities' invite services users, citizens or beneficiaries to participate. Cornwall says these spaces are always already permeated with the power effects

of difference regardless of rules for open and free exchange. In other words, spaces are not neutral. They are infused with existing relations of power interactions within them and may come to reproduce rather than challenge hierarchies and inequalities (Cornwall 2002). Furthermore power relations influence who enters and what is discussed;

Claimed or created spaces are claimed or created by less powerful actors or can emerge organically out of sets of common concerns. They can also be naturally occurring spaces were people gather to debate discuss or resist outside the institutionalised policy arenas. (Cornwall 2002). Clearly, those who create the space are likely to have more power within it, and those who have power in one may not have the same power in another. Cornwall suggest situated ethnographic and historical research as methods to understand the potential of participation (Cornwall 2004).

Ideas about power were central to both Foucault's theory about how subjects are constructed through dividing practices and also to Cornwall and Gaventa's theories on how spaces for participation are created.

Power relations in spaces for participation

Power relations help define boundaries of participatory space (Gaventa 2006). Using ideas of boundary from Foucault and others Hayward (1998) sees power as 'the network of social boundaries that delimit fields of possible action' and freedom as 'the capacity to participate effectively in shaping the social limits that define what is possible'(Hayward 1998).

An analysis of power relations which surround and fill new spaces for democratic engagement is warranted in order to assess of their transformative potential (Gaventa 2004). Power is one of the most elusive notions in the social sciences (Navarro 2006). Weber's pioneering definition saw power as 'the probability that one actor in a social relationship will be in the position to carry out his or her/ will without resistance regardless of the basis on which this probability rests'(Webber 1978). Since Webber, Lukes and Foucault have contributed much to discussions and development of thinking on Power. Bourdieu proposes social theory which provides a framework to power structures and relations (Navarro 2006). Hayward (2002) points out several questions remain for those wishing to understand power relations including 'who has power'. Sherry Arnstein (1969) sees citizen participation as citizen power. In

participation discourse Arnstein's 'Ladder of Citizen Participation'," is often quoted, it describes power structures and how they interact. Specifically it is a guide to seeing who has power when important decisions are being made. According to Arnstein, citizen participation should be the 'redistribution of power that enables *havenot* citizens, presently excluded from political and economic processes, to be involved in the future'. Without this redistribution of power participation can be an 'empty and frustrating process' (Arnstein 1969a).

Foucault saw power as not something held or static but as flowing and circulating and changing defining both spaces and subject positions. He states that 'space is fundamental in the exercise of power' (Rainbow 1984).On the other hand, Bachrach and Baratz typology assumes power relations are static and indeed that conflict is explicit. If so, a continuum of coercion, influence, authority, force and manipulation may be observable (Bachrach and Baratz 1962) .

In analysing power relations, how decisions are made is very important. Dahl describes his 'intuitive idea of power' as : A has power over B to the extent that he can get B to do something that B would not otherwise do (Dahl 1957). Implicit in this one dimensional view of power as Lukes (2005) calls it is the requirement for A and B to declare what they would or would not do. If this is declared and at odds then there is conflict. Power for the pluralists on the other hand "can be analysed only after careful examination of a series of concrete decisions and then determining the outcome" (Lukes 2005). Behaviours in how decisions are made on contentious issues where there is observable conflict can then be observed (Dahl 1957). Others argue that the pluralists' focus on explicit decision making takes no account of the fact that power may be, and often is, exercised by confining the scope of decision-making to relatively safe issues. Also they observe that the model provides no objective criterion for distinguishing between important and unimportant issues arising in the political arena (Bachrach and Baratz 1962).

The two dimensional view of power allows entry of certain interests and actors through analysis of 'mobilisation of bias' which refers to a set of predominant values, beliefs, rituals, and institutional procedures (rules of the game) that operate systematically and consistently to the benefit of certain persons and groups at the expense of others (Gaventa 2006;Lukes 2005).

However in both the one and two dimensional view of power the assumption is that the interests are consciously articulated and observable. The third dimensional view of power allows for:

consideration of the many ways in which potential issues are kept out of politics, whether through the operation of social forces and institutional practices or through individuals' decisions;. This, moreover, can occur in the absence of actual, observable conflict, which may have been successfully averted- though there remains here an implicit reference to potential conflict. This potential, however, may never in fact be actualised (Lukes 2005).

This is described as 'a latent conflict', which consists of a contradiction between 'the interests of those exercising power and the real interests of those they exclude'. This form of power operates through internalisation of powerlessness or through domination ideologies values and forms of behaviour (Gaventa 2006). It influences how individuals think about their place in the world, shapes beliefs, sense of self and acceptance of the status quo (VeneKlasen and Miller 2002). To analyse power relations where conflict is not evident Polsby suggests the researcher 'should study actual behaviour, either at first hand or by reconstructing behaviour from documents, informants, newspapers, and other appropriate sources' (Polsby 1960)

Gavanta's work aims to make the implicit power perspective more explicit. He argues that Luke's three forms of power should be understood in how spaces for participation are created (Gaventa 2006).

Clearly, involvement in decision making is necessary for 'meaningful' involvement. With this in mind Walt's ideas of decision and non-decision making contributed to the interpretive frame. Walt (2006) sees the distinction between policy and decision making as blurred and notes that ad hoc decisions may together add up to forceful implicit policies. She sees policy making as a political process rather than an analytical problem solving one. Walt acknowledges that *non* decision/ policy making is an important consideration in how policies/decisions come into being. Policy makers may decide *not to decide* on a particular issue but to delay it. Issues may remain latent or fail to enter the policy making processes because they are against the interests of those in power. A non-decision results in suppression of any challenge that seems to conflict with the interests of the decision maker (Walt 2006). Certain issues or groups are neglected or ignored. Non-decision making is in keeping with Antonio Gramsci's theory of

hegemony as it helps make the dominant view unrecognisable and therefor unchallenged (Slim and Van Loon 2001).

Deconstruction

While the above theories were used to help interpret finding Derrida's notion of deconstruction helped explain findings from the study as whole and moves towards hypothesis building. The original concepts of relationship between divisions and definition as well as the conceptual dichotomy evident in health care policy, systems approaches and in the varying perspectives on Primary Care led me to explore Derrida's deconstruction as a way of thinking about such paradoxes. Jacques Derrida used deconstruction to challenge some of the accepted ideas that have permeated philosophical thought since the time of Plato (Rolfe 2005). Derrida situates the paradoxical within a particular model thereby destabilizing the truth or unequivocal value of that model (Wolfreys 2007). The key to an understanding of deconstruction is the aporia (literally an impassable path) which Derrida denotes a logical dilemma that can neither be resolved nor worked around. A key strategy of deconstruction is to expose the aporia which exists just below the surface of all texts (Rolfe 2005). In the conclusion I expose contradictions present in the community involvement ideology in the context of current framing of Primary Care in Ireland.

While this study critically examines the health care systems increasingly referred to as Primary Care in an Irish inner city context it does so with its lens focused on involvement of community. Theories of community involvement are critiqued in the next section (chapter 2). Theories of Primary Health Care and community development are important in this context particularly as the Irish system through its evolution has been influenced by these ideologies through returning workers and missionaries from developing countries. There has also been a significant emphasis on community development through the government's programme to resource and support community organisations to tackle poverty (Motherway 2006).

In summary, increasing health system development has been prompted by a flurry of national policies and strategies which advocate equity fairness and accountability. The principle of participation and involvement of community go hand in hand with aims towards a patient centred health system. However there is suggestion of conflicting principles and policies which

support a reform process to provide a centralised consumer based system at the expense of principles of citizenship through representative democracy. Also the complexity of the Irish health care system which relies on private business men and women (with private and public patients) who may not share a vision of Primary Care with policy makers, makes realisation of these policy aims challenging at least. The evolving health system and aspirations of power sharing through involving community in decision making create a context in which I critically examine Primary Care systems and their capacity to be influenced by those they are established serve.

Structure of this thesis

In chapter two I unpack the concepts central to the area of study. I locate the development of the community involvement in the Primary Health Care movement and discuss the relationships between similar and overlapping concepts. This leads to a discussion of the theme 'participation'. I highlight some of the paradoxes of participation, particularly in state/ authority promotion of peoples' participation. I describe the successes and failure of community involvement/participation in health development in the past and finally place the concept of involvement in the policy and national context.

In chapter three I describe the approach I used in conducting this research. I describe my position as participant observer and my varying roles in the different spaces I occupied which allowed me access to community groups, residents and Primary Care providers in north inner city Dublin. I describe my data collection and analysis methods and provide a chronology of my field work as well as the rationale for focus on the sites chosen.

Chapter four sets the scene for the data chapter that follow. It describes the policy context surrounding involvement in Primary Care structural changes which aim to bring the two cultures providing Primary Care services together.

Chapter five sets the scene in terms of location, population and health. This chapter describes a changing and developing part of Dublin city with black spots poor health and deprivation. This macro view is complemented with a micro view which focuses on the Primary Care provision in the area.

Chapter six through a professional health lens at Primary Care and describes Primary Care provision on the ground in the study area. Here I use the Public Health Nurse (PHN) and the General Practitioner (GP) to illustrate Primary Care practice.

Chapter seven presents findings from my exploration of the community sector in north inner city Dublin. Community action and priorities are described through a focus on the development and workings of the community and voluntary sector operating under the Inner City Organisations Network (ICON). It identifies and describes spaces for community participation as well as involvement in health. It discusses power through an example of decision making regarding the planning of one Primary Care Centre.

Chapter eight presents an attempt to influence services through action research. This chapter describes the assessment of drug users' views through focus groups. It then takes an advocate ethnography approach to influencing health services according to drug users views. The project engages with service providers to push service users' agenda. Processes and outcomes of the project are monitored and reported. This model is evaluated as a space for participation and power relations in this domain are discussed.

Chapter nine describes the development and activities of the North Inner City Partnership in Primary Care and efforts made to involve community. It looks at power relations and decision making within this space which results in its closure.

Though analysis and discussion for each of the chapters is presented at the end of each the final chapter (10) brings the main threads together under the heading of space, power and interests. The second part of the last chapter discuses findings through the lenses of deconstruction and definition to show the framing of Primary Care affects interpretations of involvement.

Chapter 2 Literature Review

This section is divided into four: the first discusses the conceptual difference between Primary Care and Primary Health Care and describes the social determinants of health which on which the difference is based. The second explores the meaning and origin of central concepts, in both developing and developed countries. The third describes the purposes and types and experience of community involvement in health.

Primary Care and Primary Health Care: a conceptual diffference

The literature on Primary Care and Primary Health Care has been confusing in terms of the difference between the two concepts. Althought they represent different aspects of the development and articualtion of first level care the two concepts are often used as synonyms (Bhatia and Rifkin 2010;Boerma 2006). The standard approach has been connected with the WHO Alma Ata Declaraltion in 1978 on Primary Health Care, in which the focus was on solitarity and equitable access to care; on protection and promotion of health rather than curing illnessss; on inlfuence of the population rather than medical dominance and; on intersectoral collaboration in dealing with community problems (WHO 1978). Primary Health Care arose in the context of developing countries in the post-World War II era. In this context the concept represents quite a different approach to the health systems approach in most developed countries where health care provision focuses mainly on curative care, is based in institutions and mainly in the hands of the medical profession (Macdonald 1992).

In his book 'Medicine in its Place' MacDonald traces the development of the Primary Health Care movement which he argues was a response to the 'failures of western system of medical care' to tackle the health problems of poor countries. He gives many examples of how 'medico- technical' solutions provided by expensively trained health personnel could not address the health problem of populations whose symptoms are caused by for example, lack of food, lack of safe water and sanitation and ultimately to a lack of control over resources. The answers to the problems of ill health of millions lay therefore outside the health sector and in areas such as agriculture, education and sanitation and concepts such as control of resources (Macdonald 1992).

The confusion between Primary Health Care and Primary Care persists (Bhatia and Rifkin 2010(Bhatia and Rifkin 2010). Experts agree that the distinction rests on the view that health is

a reflection of the wider socio-economic determinants while Primary Care is usually seen as the delivery of services at the first line of contact by people within the health system (Bhatia and Rifkin 2010b;Murray and Frenk 2000;Rifkin and Draper 2000a). The latter reflects the western interpretation and does not engage with the wider analysis of conditions in which the poor health problems were created nor seriously engage in activities to promote equity and community participation (Murray and Frenk 2000).

In an attempt to clarify the relationship between the two concepts the Report of the Commission on the Social determinants of Health state:

The Alma Ata declaration promoted Primary Health Care as its central means toward good and fair global health - not simply health services at the Primary Care level (though that was important) but rather a health system model that acted also on the underlying social economic and political causes of poor health (Commission on the Social Determinants of Health 2008)

Social determinants and health inequalities

Dahlgren and Whitehead (1991) describe a social ecological theory to health. They attempt to map the relationship between the individual, their environment and disease. Individuals are at the centre with a set of fixed genes. Surrounding them are modifiable influences on health. The first layer incudes personal behaviour and ways of living that can promote or damage health, for example the choice to smoke or not. Individuals are affected by friendship patterns and the norms of their community. The next layer includes social and community influences, which provide mutual support for members of the community in unfavourable conditions. Social and community influences can also be negative with no support being provided or indeed worse. The third layer includes structural factors: housing, working conditions, access to services and provision of essential facilities. Finally the outer layer contains socio economic cultural and environmental conditions.

Figure 1. The social determinants of health

The social determinants of health model shows how in the context of severely negative environmental social conditions in the outer layers health and welfare is affected regardless of medical solutions. Primary Health Care therefore aims to influence outer layers whereas Primary Care generally does not. MacDonald uses malnutrition to demonstrate the inappropriateness of the medical intervention alone where causes are largely socially determined:

> A child suffering malnutrition is presented to the clinic where he is examined by a clinician, weighed measured and a diagnosis made. The diagnosis may be marasmus or kwashiorkor. Treatment may include admission to inpatient care for therapeutic feeding after initial stabilisation and antibiotic treatment of any coexistent infections or prophylactic antimicrobial therapy in recognition of immunodeficiency. Many mothers will not allow the admission to inpatient facility as there will more often than not be other family members depending on her for survival. Many others will not be able to afford whatever the clinician has prescribed. Many children in this condition after meeting the clinician will die. The cause of the malnutrition in most cases will not have been identified, if it has it will most likely been related to infection or maternal

ignorance on adequate nutrition. Poverty and lack of control over resources are often the real problems (Macdonald 1992a).

It is not difficult to see how in socially disadvantaged areas strictly medical solutions can often fail to provide effective solutions either because the causes are largely routed in the outer layers the social determinants model or because the solutions are impeded by structural barriers. The negative relationship between socioeconomic deprivation and health is well documented and is often mirrored by inequalities in access to health care (Tudor Hart 1971). An example of this is that there is a much higher prevalence of Hepatitis C in the homeless population yet only half have medical cards (giving access to free health care) and treatment for Hepatitis C requires stable living accommodation (O'Carroll and O'Reilly 2008).

The risk of poor health increases for those furthest down the socio-economic scale (Layte, Nolan, and Nolan 2007). The All Ireland Study on Mortality 1989-1998 showed that there was a three-fold difference in age-standardised death rates between men in the lowest and highest socio–economic groups during the period 1989-1998. The strong impact of occupational class was evident for nearly all the major causes of death. When the lowest occupational class is compared with the highest there are major differences in mortality (Balanda and Wilde 2001).

The development of Primary Health Care

Primary Health can be traced to the 19th-century German physician, pathologist and anthropologist Rudolf Virchow who is credited with being one of the early founders of social medicine. He believed that the solution to major human disease problems resided not only in the best science available but also in 'brave political proposals' for social justice and the improvement of the life of the poor (McNeely 2002). He saw health as not only a by-product of social changes but an instrument to promote such changes (Cueto 2005).

Primary Health Care emerged in a new political context: the end of the cold war and the decolonization of African nations. With political independence many countries found themselves committed to social improvements. PHC was a potential solution to the fact that half of the world's population had no access to healthcare, the 'vertical' programmes for endemic diseases like malaria were not working, and trying to expand the elitist hospital system in existence during the colonial period was not an option. This model which was

expensive, curative and focused on medical treatment services could not impact significantly health of large populations in these countries. The novel notion was that it challenged the assumption that health resulted from the transference of technology or more doctors and more services (Cueto 2004).

The idealistic strategy was to bring health to all, particularly those hard to reach in rural communities. The three pillars of the strategy were participation, intersectoral collaboration and equity. It aimed to tackle diseases of poverty and ensure that most people had access to basic health services. It emphasised that medical technology should be appropriate to the needs of the people, scientifically sound, and financially feasible. Health posts in rural areas and shanty towns were built instead of hospitals. Lay people were given basic health training and specialisation of health personnel in developing countries and of top-down health campaigns were not encouraged. Community participation was a central theme (Macdonald 1992a). The Alma Ata declaration defined PHC as:

Essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process (WHO 1978)

An important early influence, which shows the importance of context, was the massive expansion of rural medical services in Communist China through the 'barefoot doctors' (Cueto, 2004). The expansion occurred as part of the Cultural Revolution in China in the sixties and seventies. As part of this, doctors settled in rural areas and trained 750,000 farmers with basic medical training - 'barefoot doctors', thereby narrowing the gap between urban and rural medical services. The end of the Cultural Revolution led to a rapid and drastic decline in the healthcare system in the countryside. The barefoot doctor system was abandoned by Deng's regime in 1981 (The MIM Revolutioary study group 2007). Though a product of the cultural

revolution in the People's Republic of China at the time, the WHO depoliticised the 'barefoot doctors' by focusing on (and trying to transfer) the characteristics (access by all to basic care provided by rudimentary trained workers close to the people) rather than the context which was politically and culturally driven (Navaro 2002a).

Primary Health Care was open to a range of interpretation from, in its most radical form, the complete reform of public health systems and the promotion of social change, to merely serving as an entry point to a professionalised health system or an extension of services to underserved areas (Cueto 2005). The radical form challenged power relations in particular the medical dominance in health care provision (Macdonald, 1992) whereas the 'instrumental' view is according to Ceuto, about poor medicine for poor people.

Eventually the Alma-Ata Declaration was criticised for being too broad and idealistic. About a year after the conference took place a more focused definition was identified and called 'Selective Primary Health Care'. This focused on distinct strategies (e.g. vaccination) to deal with specific causes of death, paying special attention to the most common diseases of infants. In the following years, these low cost technical interventions were reduced to growth monitoring, oral rehydration techniques, breastfeeding, and immunization (Cueto 2004).

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People's participation is a cornerstone of the Primary Health Care model having been introduced as a right and duty by the WHO in the Alma Ata declaration:

People have a right and a duty to participate both individually and collectively in the planning and implementation of their health care (WHO 1978).

The role of community participation in Primary Health Care cannot be overstated. Most experts and commentators considered it the 'heart of Primary Health Care' (Rifkin,1986),as 'essential' (WHO and UNICEF 1978b) and 'central' and the 'solution' for all the 'massive problem' of the world (Jewkes and Murcott 1998).

Primary Care today

Primary Care in the context of developed country health systems generally does not encompass the broad societal strategy laid out for Primary Health Care at Alma Ata, but rather a subset of functions or services delivered usually as the first level of the formal health care system. It can be understood as the professional response when patients make contact with the health system. It is generally broader than services provided by a general practitioner or family doctor and considerably narrower than the concept put forward at Alma Ata (Boerma 2006). Starfield (1994) traces the development of the three major levels of health care services; primary health centres, secondary health centres and teaching hospitals, back to a 1920 white paper in Great Britain. This theoretical arrangement provided the basis of health services in many countries which have clearly defined levels of care, each with a primary medical care sector.

The first contact does not necessarily imply progression to diagnostic treatment in other parts of the system and from other disciplines. For many, no further intervention is warranted. However if more than one health professional is warranted coordination is necessary to avoid duplication and safeguard continuity. The functions of Primary Care have been summarised in the definition of the American Institute of Medicine (Donaldson et al. 1996) as follows:

> The provision of an integrated , accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients and practicing in the context of family and community.

Under varying banners but usually including an indication of first level (primary) the term has been used to describe services provided by clinicians solely e.g. general practice (Brown 1994b;Smith 2010b). Hannay describes Primary Care as and a mix of services and features

including social services and participation as well as primary medical care (Hannay, Sunners, and Platta 1997). Yet another interpretation - Community Orientated Primary Care (COPC) emphasises the identification and treatment of the main health problems of a defined population. A team of health professionals and community members work in partnership over a long period of time. It contains principles of Primary Care, epidemiology and public health. While Primary Care professionals are not necessary for every project, the community is a partner at every step (Rhyne et al. 1998).

Across Europe general practice is often seen as a core discipline in primary care practice and though difficult to conceptualise without it, the two concepts are not equivalent. Nursing is also a crucial profession seen in various forms in Primary Care, the longest tradition of which involves community nurses who care for people in their own homes. Pharmacists, physiotherapists and home helps are some of the other professionals involved in Primary Care throughout Europe depending on the country context. When more than one provider is involved in a patients care some form of coordination is needed. Boon et all describe various types of health care service provision along a continuum from parallel working to integrative care (Boonet al. 2004) . The integrated team is the aim of good health care systems which is achieved by interdisciplinary team based on a shared vision, 'a seamless continuum of decision making and patient centred care and support'. One of the main reason why health care and primary care are not very coherent or cost effective is that coordination and teamwork are difficult to achieve (Boerma 2006).

Most commentators acknowledge that the crystallisation of the concept of Primary Health Care formulated at Alma Ata had a major impact on the thinking about Primary Care. Starfield notes however the disagreement about the extent to which it was thought applicable to industrialised countries contexts (Starfield 1992b). Many of the goals of Alma Ata (food supply, safe water, maternal and child health, immunisation, prevention and control of endemic diseases, basic treatment of health problems and provision of essential drugs) had been proudly attained by industrialised countries (Vuori 1984). The emphasis on 'nearness' to people was alien to contexts based on technology specialisation and the primacy of the hospital. Requirement that care should be 'needs based' was not understood where there were well established health systems but no information system to document needs or the impact of the health care system on them. The 'community orientation' had little historical

basis in the health system of most industrialised countries (Starfield 1992b). Starfield describes Primary Care as something that is between Primary Medical Care and Primary Health Care as she puts it, 'Conventional primary medical care striving to achieve the goals of Primary Health Care.'

Section summary

Conceptually then, Primary Health Care is based on principles of equity, intersectoral collaboration and community participation. Primary Care generally includes medical care, public health programmes, and some social services and strives for community participation but does not necessarily attempt to tackle the social determinants of poor health (Bhatia and Rifkin 2010;Deane 2004a;Hannay, Sunners, and Platta 1997;Macdonald 1992;Starfield 1992). In its most radical form Primary Health Care was seen as being capable of the complete reform of public health systems and the promotion of social change. In its meekest form, it merely served as an entry point to a professionalised health system or an extension of services to underserved areas (Cueto 2005). The radical form challenged power relations in particular the medical dominance in health care provision (Macdonald 1992) whereas the 'instrumental' view is according to Ceuto, about poor medicine for poor people.

Certainty difference between the concepts lies in the community orientation and the power of people to influence and participate necessary for Primary Health Care are as well as the fundamentally means a shift away from medical solutions.

The literature sees those like MacDonald who champion Primary Health Care as a radical and necessary challenge to medical power and on the other hand those like Navaro who see it as a hegemonic response to the problems of developing countries. The problem as he saw it was the pattern of world-wide power relations: few having control over the world's resources. Redistribution of resources worldwide was in his view what was required, not the appeasing strategies. He sees the Alma Ata declaration and associated report's as part of this strategy which he says, represent the perspective of the dominant classes (Navaro, 2002).

Central concepts: meaning and ideology

This section discusses the meanings of central concepts and ideological influences underpinning theories and thinking about community involvement in health. It discusses what community means and differences in ideologies about who it refers to and what constitutes meaningful involvement. The development of approaches to participation and community development are discussed. The sections highlight the variety in interpretations of central concepts and points out some inherent paradoxes present in theories and approaches to participation in development.

Bandesha and Litva (Bandesha and Litva 2005) note that converting the rhetoric of community participation in health into reality is a greater challenge than was envisaged by policy makers. Community involvement or participation in health means many different things to many different people dependent on purpose, ideology and perspective. Some suggest that the notions 'all things to all men' appeal is central to its success (Harrison and Mort 1998b;Morgan 2001a) while others blame the slow escalation of involvement at least in part on the myriad of ways in which it is conceptualised and discussed (Forbat, Hubbard, and Kearney 2009). However, that which makes the construct popular also contributes to its potential deconstruction as more authors and practitioners are now willing to question whether community involvement is all it seems (Hickey and Mohan 2004a).

Many researchers deal pragmatically with definition and define a priori what central concepts in the study question or topic mean to them and forge ahead from a justifying perspective (Anderson, Shepherd, and Salisbury 2005;Ridley and Jones 2002;Ridley and Jones 2010). I feel that the fact that central concepts/constructs have multiple meanings with multiple origins and influences impacts how and whether various interpretations and policies based on those interpretations are or can be implemented. I have therefore chosen, to explore the historical development and context of these constructs. I feel that the developing world context and use of these constructs was particularly important because this was the version of community involvement imagined at the start of this study.

What is community?

While there is generally a shared understanding in the health literature of communities as groups linked socially and geographically other forms of communities who may not share geography are also recognised (Rifkin and Draper 2000a;WHO 1986).

Communities have been described as heterogeneous entities, whose diversity can be problematic when it comes to representation and accountability (Zakus & Lysack 1998). Community can be seen in its geographic sense i.e. people living in the same place or neighbourhood. It can be seen as a collective with similar characteristics or in terms of beliefs or interest (e.g. monastic community)(Waite, Hollongworth, and Marshall 2005). The Alma Ata declaration which put community participation at the centre of the World Health Organisation (WHO) member state national health policy did not define community (WHO 1978;WHO and UNICEF 1978). However, some authors argued that the definition which was implied was that community was a geographically located group of people with shared economic, social-cultural and political interests as well as shared problems and needs (Jewkes and Murcott 1996). In later documentation, the WHO defined community on the basis of locality or neighbourhood, social relationships, and or a shared identity or common interest e.g. village, part of a city, drug users, gay community, community of sex workers (World Health Organisation 2001). A study looking at this definition in order to support community based public health initiatives found a common definition of community emerged as a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings (MacQeenet al. 2001)

In the health literature there is a tendency to define community in terms of geography. Some suggest that this may reflect epidemiologist's view to target interventions within geographical boundaries (Rifkin, Lewando-Hundt, and Draper 2000). Other definitions require no such boundaries. The Ottawa Charter for health promotion bases its definition on social units as well as formal administrative units (WHO 1986). Jewkes and Murcott (1996) note the 'singular lack of specificity and agreement about what the *community* whose participation is regarded as so essential actually is'.

What is community Involvement?

Meaning of 'community involvement in health' appears more elusive than meaning of community in the literature. It has been viewed as an idea, an ideology, a concept, a means to improve health or an end in itself, is dependent on perspective. There is little consensus across interpretations of what it is, how it should be implemented and what its benefits and indeed its detriments are. Though there is considerable confusion as well as variation about meaning and purpose, nevertheless in democratic societies the idea of community involvement in health care has become part of health policy rhetoric (Anderson, Shepherd, and Salisbury 2005;Entwistle 2007;Farrell 2004b;Ridley and Jones 2002;Rifkin 2001;Rowe and Shepherd 2002;Simces 2003). Though distinctions have been made between the terms community *involvement* and community *participation* (WHO Study Group 1991), most of the literature uses these interchangeably (Rifkin, Lewando-Hundt, and Draper 2000).

The definition developed at the 1978 International Conference on Primary Health Care, sees community involvement from an outsider perspective. The language used, emphasises 'others' identifying what 'they' (community members) must do. It lays the responsibility for health squarely in the hands of the community members as well as the responsibility for finding the solutions to their own problems. The health system is only responsible for explaining and advising:

> The process by which individuals and families assume responsibility for their own health and welfare and for those of the community, and develop the capacity to contribute to their and the community's development. They come to know their own situation better and are motivated to solve their common problems. This enables them to become agents of their own development instead of passive beneficiaries of development aid. They therefore need to realise that they are not obliged to accept conventional solutions that are unsuitable but can improvise and innovate to find solutions that are suitable. They have to acquire the capacity to appraise a situation, weigh the various possibilities and estimate what their own contribution can be. While the community must be willing to learn, the health system is responsible for explaining and advising and for providing clear information about the favourable and adverse consequences of the interventions being proposed as well as their relative costs. (World Health Organisation 1978).

While it may be argued that the attempt here is to empower community members, such an approach also risks blaming people for their own ill health. Here commentators divide in opinion, some see participating and cooperating with authorities and health systems as well as taking advice and instruction from outsiders as the answer to community health problems. Others focus on the control of resources and see challenge and confrontation and ultimately a power shift, as real participation in health (Morgan 1993). The later was not what was intended by the Alma Ata declaration (Navaro 2002;WHO 1978).

Community Involvement in Health (CIH) was formalised as a concept post the Alma Ata declaration on Primary Health Care. The involvement of communities influenced the way Primary Health Care was designed and delivered (tropical disease control, immunisation campaigns, family health, water supply, sanitation) as well as planned managed and evaluated (WHO Study Group 1991).

The arguments for CIH outlined by Oakley (Oakley 1998)are summarised below

- The basic right of all: Involvement in the decisions and actions affecting health builds self-esteem and encourages a sense of responsibility
- Efficient use of resources, making services more responsive to needs and encourages coverage.
- Increases likelihood of appropriateness and success if services are linked to local's perceptions and managed with the support of them.
- Discourages dependency and encourages involvement in development.

The WHO Study group defined *involvement* as broader and a more action orientated concept than participation and concluded that there were two broad but distinct ways of promoting CIH a) through awareness and understanding of health and health problems and b) through access to information and knowledge about health service programmes and projects. The strategy in the first is to build up awareness and understanding about health determinants for future involvement in health development the second is to equip communities for involvement in the health services. The Study group concluded that: CIH is essentially a process whereby people, both individually and in groups, exercise their right to play an active and direct role in the development of appropriate health services in ensuring the conditions for sustained better

health and in supporting the empowerment of communities for health development (WHO Study Group 1991)

While the WHO definition of community participation at Alma Ata was quite 'othering' it was also quite prescriptive. CIH formalised afterwards went a long way in providing some clarity and pragmatic guidance. However CIH and indeed the WHO perspective reflected in Alma Ata had more of a resonance with the developing world contexts. The literature from the non-developing country context in particular sees little consensus on the meaning of community involvement / participation (Ridley and Jones 2002).

One attempt to develop consensus among professional and user stakeholders only achieved:

> A general agreement that users should be involved in decisions about their treatment and care and that the purpose of user involvement was to improve services. Although there was general agreement on specific aspects of user involvement, there was little agreement about who users were or how they should be involved" (Farrell 2004)

The term *users*, has been interpreted in the individual form and collectively, as well as being current, past or potentially future service users. Broad groups defined either by illness, geography, interest or service can determine user group make up. There is lack of agreement on the composition of the collective whose participation is regarded as so essential (Jewkes and Murcott 1998b). Matka researched community involvement in the context of Health Action Zones (HAZ) in the UK and observed:

> Community involvement is a catch all term understood differently by all involved in various partner agencies engaged in HAZ whether they are communities of identity and interest such as particular ethnic minorities or users of a particular health service or defined by a particular geography (Matka, Barnes, and Sullivan 2002)

Varying terms are used to describe the concept of people, in groups or populations relating with or attempting to influence the shape of services intended for their use. Definitions have been constantly re-negotiated and lack universality (Andersonet al. 2002b;Ridley and Jones 2002;Rifkin, Lewando-Hundt, and Draper 2000).

Involving who, citizen or consumer?

Varying ideologies underpinning efforts to involve are evident in the language used through the literature on participation and involvement. Ideological workings of language is the prime means though which the exercise of power through the manufacture of consent is achieved (Fairclough 2001). Among civil society groups, there is growing concern that the citizen interest is becoming marginalized as the consumer discourse becomes more widespread (Livingstone, Lunt, and Miller 2007).

There are important differences in values and interests concealed by the language of 'community involvement' and 'consumer choice' (Harrison, Dowswell, and Milewa 2002;Wistow and Barnes 1993). Terms such as consumer, citizen, client or patient, imply different power relationships and provide a clue to the ideological perspective and therefore interests of those using them (Pickard 1998). For example if the term *consumer involvement* is used by service providers, this may suggest that a professional or business like and quality image is sought. Consumer values generally focus on prioritising the delivery of services which are sensitive to individual needs and wants (Anderson, et al 2002). The use of the word consumers in relation to health also implies that services are commodities. Consumerism places a focus on commodities bought and sold on the open market. Consumerism tends to favour those with buying capacity and market forces which mean different commodities (services) compete with one another. A health system based on consumerism will tend towards different levels and types of service depending on consumers capacity to pay and one that is not necessarily coherent. *Public* involvement on the other hand, framed within a new public management perspective, holds ideas of democratisation and citizenship and requires a connection with organisational interests (Anderson et al 2002;Hogg 2007;Rowe and Shepherd 2002).

Citizenship for Marshall (Marshall 1977) was to enjoy equal rights including voting rights and entitlements as well as basic living necessities. The notion of citizenship is very much part of the rhetoric of community participation, community development and empowerment.

A key distinction is made in the literature between a consumerist model of involvement that is service led and a broader democratic model that is citizen led (Lupton, Peckham, and Taylor 1998a;Wistow and Barnes 1993). The former emphasises service-side responsibilities in

eliciting and responding to the preferences of individual consumers (Brown 2001). Compared to the rather passive forms of participation in the consumerist model, the democratic approach is strongly associated with public empowerment and active citizenship. It assumes that, as citizens, individuals have a right to shape decisions that affect their own lives and that of their communities (Coulter 2000). Much of the drive for more participative democracy resulted from failures of representative democracy and the response to criticism of the welfare state. In relation to health, trends to strengthen the users' and public's voice comes also in response to professional dominance and unregulated health authority managerial behaviour (Harrison and Mort 1998).

Rousseau (often considered the father of participatory democracy) saw participation not only a means of better governance but also as a means to make people responsible members of society. He saw this kind of participation as capable of providing people with ultimate freedom as it would give them more control over their own lives. He described participation as an obligation to the extent that the private citizen 'is *forced* to deliberate according to his sense of justice' (Pateman 1970).

Lupton et al (1998) describe a general move to recast the citizen as consumer, to give individual choice via the market place and encourage people to pursue exit strategies[1] rather than using their voices. The consumerist approach is a concern about responsiveness and choice. In this model, public involvement is principally conceived as a means of enhancing the process of service development, by more closely aligning this with the views and preferences of those who use and need health services (Coulter and Ellins 2006). A wave of consumerism saw the formation of the first consumers association also made calls for user involvement (Skelcher 1993). In the UK in the sixties and seventies patients' associations were established leading to Community Health Councils in 1974 (Agasset al. 1991). Early policies see the service user as consumers (Onget al. 1991). This view sees the user as someone who wants the service to change to meet *individual needs* whereas the view of user as participant sees the users as a *social being* who has a totality of needs of which health is one. Williams and Grant (1998) comment:

[1] Consumers can choose to stop using a service and go somewhere else providing there are accessible alternatives and that they have the ability to purchase them.

People are more than consumers. To be people centred and value individuals requires an appreciation of the totality of the individual and not concentration on a specific role. This is surely the same criticism which has been laid at the door of the medical profession: in treating people as patients they have reduced the individual and thus devalued them (Williams and Grant 1998).

While some writers see consumerism as enhancing citizenship most suggest that they are in conflict and see common identity and wider societal interest (suggested by community and public involvement) as an alternative to individualism and consumer choice (Crowley 2000;Livingstone, Lunt, and Miller 2007;Plant 1990;Ridley and Jones 2002)

Involvement in what?

A wide range of activities and functions with the potential for varying levels of influence or power are described in the literature. There is a growing consensus that for involvement to be meaningful there must be the potential to influence decision making (Cohen and Uphoff 1980;Jewkes and Murcott 1998b;Joneset al. 2004a).

Participation and involvement in any aspect of health care can include a range of activities from self-care at the individual level or self- help at the community level, to public or community control of health planning. Definitions of community participation range from people being passive receivers of a service to shaping what that service is and looks like (Fudg et al 2008;Harrison, Dowswell, and Milewa 2002;Oakley 1998;WHO Study Group 1991; Jordanet al. 1998)

Abelson (2001) sees the construct as incorporating public and community views regarding local health services. Others see it as any form of engagement; patient and public involvement have been interpreted as follows:

> All forms of institutional and professional engagement with lay people – patients carers local people, local communities, other than the individual professional – patient relationship'(Anderson, Florin, Gillam, and Mountford 2002b)

The discourse ranges from rights linked participation in health to notions of democracy to the notion of social justice with the ability to enable 'redistribution [of resources] to the poor' (Oakley 1998). In the 1970s researchers at Cornell University embarked on an international study of programmes which claimed to be participatory in order to clarify the nature of involvement. The result was a categorisation of four main types of participation; implementation, benefits, evaluation or decision making. They found considerable evidence of participation in implementation (people carrying out activities suggested by professionals) and benefits (immunisation, services, treatment etc.). Participation in evaluation and decision making was much less common (Cohen and Uphoff 1980). They suggest that these elements are necessary for 'true' participation.

The involvement of individuals in health generally centres on involvement in own care and treatment while public participation or community involvement usually concerns involvement in decision-making concerning service planning and development. This kind of involvement aims to democratise decision-making with the public assuming greater responsibility for decisions regarding the wider aspects of health and social policy (Anderson et al 2002;Jones et al. 2004). As such community involvement is thought to challenge the traditional concept of professional control and power (Brown 1994;Macdonald 1992). The concept of public or community involvement emphasises the valuing of citizen's knowledge and practice. It suggests an active participation of local people in health service organisation and delivery and in some interpretations requires that communities are supported with resources and skills to handle these responsibilities (Jewkes and Murcott 1998).

Ideologies influence what involvement may mean. For those following a community development approach for example involvement in health many not necessarily include 'engagement' with health organisations but rather aim to tackle poverty, education and poor housing and the causes of poor health (CLES consulting 2008;Combat Poverty Agency 2005a). According to WHO community participation aims include communities in defining problems, planning and organising interventions (World Health Organisation 2001). For involvement to be meaningful communities and the public must be able to participate in decisions about the development, planning and provision of health services (Coulter and Ellins 2006). This decision making emphasis is supported by Irish policy which sees community involvement as;

A process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing polices, in planning, developing and delivering services and in taking action to achieve change (HeBE 2002)

Rousseau concurs with the view that people are to be involved in 'decision making' (Pateman 1970). Vuori (Vuori 1984) argued that the emphasis in developed countries was participation in decision making while in developing countries the emphasis was on resource mobilisation to extend provision. Shared decision making is described by researchers as the 'neglected half of the consultation process' (Ridley and Jones 2002).

Theories of Participation

The development of theories of participation has been prolific through the last century and has spanned the development of all aspects of societal living, industry development, and civic society. Participation has been described as having varying levels of rights responsibilities and obligations attached. While on the surface most theories appear to challenge traditional power by allowing or 'encouraging' citizens to shape their futures and lives more recent literature challenges some of these assumptions.

Community participation in health programmes in developing countries was promoted by professional community health organisers (often from developed countries) as a way of mobilising indigenous human resources and knowledge necessary for the implementation of Primary Health Care programmes on limited budgets (Zakus and Lysack 1998). The concept began to generate enthusiasm in the mid - seventies when the Primary Health Care (PHC) movement gathered ground (Morgan 1993).

Though the genesis of community participation in health is attributed primarily to large multinational institutions, centrally the WHO, (Zakus and Lysack 1998), the approach to involve lay people in health issues in western countries dates back to the establishment of the Peckham centre in the late 1920s in the UK (Goodway 2010). This version emphasised self-help, health promotion and health advocacy (Delaney, Keegan, and McGee 2002). However the influence of the approaches to, and thinking about involvement in health have been

heavily influenced by the developing world context in particularly Primary Health Care (PHC)(Hickey and Mohan 2004;Starfield 1992).

Participation in development

Participation has been a central concern in a number of different approaches to development. Chambers (1997b) for example cites Freirean action research as a major influence on participatory development theory. Hickey and Mohan (2004b) identify four dimensions of participation which encompass:

- The locus and level of engagement.
- Ideological underpinnings of the participatory approach.
- The promotion of 'citizenship' as the goal of the participative approach.
- The links to development theory

Table1 below extracted from Hickey and Mohan, provides a selective history of participation in development. This history sees participation as fluctuating between a right and an obligation of citizenship as well as both a means of challenging marginalisation and as a project characteristic. The populist form of participation emphasised the importance of local priorities and the need for *facilitators* rather than *directive experts* to collect local knowledge and enable capabilities. Power transformation is claimed to be possible by according the participatory roles held by the 'subjects' of development (2004b;Chambers 1997b;Hickey and Mohan 2004c).

The *participatory development* construct had gone virtually unchallenged until the late nineties when doubts about the evidence that participatory approaches were living up to the promise of empowerment for marginal people, were captured in a book entitled 'Participation: the new tyranny?' (Cook and Kothari 2001). The authors of 'Participation from tyranny to transformation' address criticisms of the concept but maintain a sceptical note and rigorously challenge assumptions. The authors claim that participatory development has often failed to engage with issues of power and politics and has sometimes become a technical approach to development. The underlying theme in the book is that understanding the ways in which participation relates to power structures and political systems provides a basis for an approach that is more potentially capable of effecting change (Hickey and Mohan 2004).

Table 1 Selected history of participation in development theory

Era	Approach	Institutional and intellectual influences	Approach to citizenship	Locus/level of engagement
1940s – 50s	Community dev (colonial	UK Colonial office	Participation as an **obligation** of citizenship; citizenship formed in homogenous communities	Community
60s-70	CD post-colonial	Post-colonial governments (social welfare departments)		
60s	Political participation	North American political science	Participation as a **right and obligation** of citizenship (e.g. voting, campaigning political party membership)	Political system and constituent parts; citizens
60-70s	Emancipatory participation. Liberations theology (LT)	Radical Sothern researchers, educationalists (Freire, Fals Borda, Rahman). 2nd Vatican council, Latin America, catholic priests. Gutierrez, Sobrino	As a **right and means of challenging** subordination and marginalisation	Economic and civic spheres; communities ; citizens
70s	Alternative development	Dag Hammarskjold conf 74. Development dialogue, Nerfin Fredman	As a **right of citizenship**; citizenship as a key objectives of alternative development to be realised in multi-level political communities	Initially communities and civic society, latterly on the state through 'inclusive governance'
80s	Populist participation in development	Development professions NGOs World Bank Participation Learning group, UN agencies. Chambers	Focus on **participation in projects** rather than in broader political communities	Development professionals and agencies; local participants
Mid 90s	Social capital	World bank social capital and civil society working group. Putman, Bourdieu, Narayan	Participation **as a right and obligation** of citizenship	Civic associations
Late 90s-present	Participatory governance and citizenship participation	Participatory research and action (Delhi). Institute for development studies Brighton (Participation Group)	Participation as primarily a **right of citizenship**	Citizens, civil society state agencies and institutions

Community development

The first conceptual framework described in the next chapter (page 97) which was the initial guide for fieldwork was underpinned by theories of community development. As such theory surrounding this construct is important. Community development has been described as being synonymous with community participation, a form of participation (Abbott 1995), a way to achieve participation and as a movement which relies on participation (Rifkin, Lewando-Hundt, and Draper 2000). Community development generally encompasses features of empowerment, needs identification and the ability of the communities themselves to effect change. There is inherent paradox in that development of the construct itself arose from retreating colonialists from Africa (Foster 1982). The paradox is continued with the tendency for community development to be supported (as in Ireland) by the very powers that might be challenge (Abbott 1995;Rifkin and Draper 2000).

Community development emphasises community empowerment and does not require connection with institutional health care systems. It often prioritises addressing the social causes of ill health e.g. poverty and exclusion (Crowley 2004;Fisher 2009;Heritage and Dooris 2009;Kahssay and Oakley 1999). Crowley (2000) describes community development as an approach which 'ensures that the community is involved from the start and decides for itself what the priority areas are'.

Just as there are varied interpretations on meaning of community involvement in health there are varied perspectives about what community development is and who it involves. Some views see the focus on *enabling* communities to define and resolve problems in their local areas rather than engaging them in dialogue within organisational structures (Andersonet al. 2002;Andersonet al 2002;Frank and Smith 1999). Others encourage self- help but also engagement with other groups and partnerships for the purpose of influencing services (Crowley 2000;DHSS 1997). Rifkin (2000) categorises the varying perspectives as a means of i) spreading participatory democracy ii) empowerment and iii) as a programme based on muti-sectoral community led needs, self- planning, self- reliance, capacity building and resource support.

A simple definition sees community members getting together to solve their own problems;

> A process whereby community members come together to take collective action

and generate solutions to common problems' (Frank and Smith 1999).

Lee's definition emphasizes rights and involvement in decision making. He sees community development as being rooted in a broad understanding of citizenship that sees people as having a right to influence and participate in the decisions that affect them and to have their experiences and views listened to and acted on. Community development, he sees as potentially a means or process whereby people can achieve this right (Lee 2003).

The statutory body Combat Poverty Agency (CPA), has greatly influenced the Irish interpretation and experience of community development which centres on anti- poverty, empowerment and participation (Combat Poverty Agency 2005). The CPAs definition combines both of those above but adds focus on those who have been alienated from decision making - marginalized or people living in poverty;

> The long-term process whereby people who are marginalised or living in poverty work together to identify their needs, create change, exert more influence in the decisions which affect their lives and work to improve the quality of their lives, the communities in which they live, and the society of which they are a part. (Combat Poverty Agency 2005).

Labonte's (1993) definition of 'community development and health' sees community groups as the target of 'support' and efforts to increase their involvement in decision making;

> the process of organising and/or supporting community groups in identifying their health issues, planning and acting upon their strategies for social action/change, and gaining increased self-reliance and decision-making power as a result of their activities.

Smithies (2004), recognises three main features that separate community development from other forms of community based work. These are challenging social exclusion, poverty, disadvantage and discrimination, strengthening communities and influencing policy through community involvement.

Over time community development in the UK has ebbed between community work and social activism being influenced by developments in the US (Baldock 1980). The origins of community

work in the UK sees the 'privileged' as being necessary for the development of the 'poor' while at the same time and perhaps paradoxically promoting the concept of self- help. The first University Settlement which Cannon Samuel Barnet founded (Toynbee Hall) in London in 1884 prompted the privileged to go and live among the poor. From this a significant social welfare and education programme grew (Smith 1997).

In the United States the history of community development can be traced to Roosevelt's establishment of the Country Life commission in 1908, and activities to improve life for rural Americans through creating local organisations. It developed along a social activist route focusing on supporting and organising poor communities to demand and get resources from authorities (Rifkin, Lewando-Hundt, and Draper 2000).

In the post-world war II era, the emerging concept was embraced by post colonising governments. The first widely accepted definition of community development came out of the 1948 Cambridge Summer Conference on African Administration. This definition provides an either or, option which allows for external support if communities are not 'doing it' themselves.

> A movement designed to promote better living for the whole community with the active participation, and if possible on the initiative of the community, but if this initiative is not forthcoming spontaneously, by the use of techniques for arousing and stimulating it in order to secure its active and enthusiastic response to the movement.' (Foster 1982)

The major concerns of the departing colonial powers from Africa and Asia was to ensure that the economic and social patterns established in the independent countries would ensure stability and continuing ties with the 'motherland' while minimising dependence (Baldock 1980).

In Ireland the concept originates in the co-operative development movement in the early 19th century and then in the establishment in the 1930s of Muintir na Tire based on a philosophy of self-help (Lee 2003). It was generally seen as a 'conservative' movement with close ties to the clergy (Motherway 2006a). In this respect it reflected the UN definition of community development at the time, which saw it as a process complementary to governments goals;

The processes by which the efforts of the people themselves are united with those of Governmental authorities to improve the economic, social and cultural conditions of communities, to integrate the communities into the life of the nation, and to enable them to contribute fully to national progress (UN Dept.of Economic and Social Affairs 1971)

However in the sixties, emphasis on collaboration changed to a focus on social change, this occurred initially without state support (Kelleher and Whelan 1992a). Between the sixties and the nineties the community development movement in Ireland experienced significant growth, there was a move towards community-based social services, a growth in community projects focused on unemployment and also in self-help and direct action groups, and a renewed interest in the structural dimension of poverty at national and EU-programme level (Lee 2003). The seventies brought an emphasis on poverty with the government's first programme to resource and support community organisations to tackle poverty. The Poverty Two programme (1985-1990) led to the establishment of the first community development Fund in 1990.This was characterized by the emphasis on community development as an approach to tackling poverty, closer state relationships and the centrality of social partnership (Motherway 2006c).

Section Summary

Community involvement in health has a traceable genesis in both developed and developing countries. The formulation that is influenced by the developing country context is linked through ideology and governing principles to community development and the Primary Health Care movement rather than consumerism which is more identified with developments in the west.

Though there is considerable confusion as well as variation about meaning and purpose of community involvement it is generally seen as a good thing. Participation in development theory over time sees changes in emphasis on rights responsibilities and obligations. Theory is also affected by ideology which constructs people as consumer or citizen. The consumerist model of involvement is service led and a broader democratic model is citizen led (Lupton, Peckham, and Taylor 1998;Wistow and Barnes 1993). While on the surface most theories appear to challenge traditional power by allowing or 'encouraging' citizens to shape their

futures and lives there is a growing body of literature challenging some of these assumptions (Cooke and Kothari 2001a;Morgan 1993b;Navaro 2002b).

Community development has been described as being synonymous with community participation, a form of participation (Abbott 1995), a way to achieve participation and as a movement which relies on participation (Rifkin and Draper 2000). Community development in Ireland has had varying positions in relation to power; initially on the outside but unchallenging, then challenging the power structures from the outside to partnership with and being funded by the government. Interpretations vary and some experts believe there are problems internal to the construct itself. These centre on the necessity for stimulus to come from outside the community and the approaches' inability to address power imbalance (Abbott 1995;Rifkin and Draper 2000).

There is overlap and paradoxes among and between central theoretical concepts such as government sponsored involvement, forced participation and externally stimulated community development. The paradox continues with the observations that increased participation is unnecessary where state are responsible and services meet needs yet such contexts are deemed necessary by some for successful participation.

Purpose, types and experience

This section looks at the purported purposes of involving communities in Primary Care and the findings reported in the literature of outcomes according to those purposes. Different rationales for involving people in health decision making are reported throughout the literature including ideological reasons, aims to improve services and outcomes and aims to improve decision making and transparency. Attempts to add clarity to the subject has resulted in typologies which are presented. The section ends with and overview of the experience of community participation and involvement in developing countries and developed countries.

Purposes and effects of community involvement in Primary Care

The rationale for the involvement of communities or the public in health is varied. There are potential benefits to the service (e.g. improved public confidence); to people (e.g. more responsive services); to public health (e.g. improved health); and to society as whole (e.g. building social capital) (Coulter and Ellins 2006). Charles and De Maio (1993) identify three motivations for participation in health care decision making. The first is because it is valued as an end in itself; the second is to improve decision making and the third to improve health status. The motivation to involve community and public can also be seen as a *means* to improve services or health status on an *end* in itself (Coulter and Ellins 2006;Oakley 1998;Rifkin and Draper 2000a). As a means, goals include making services responsive to users' needs. This is linked to the view that participative processes contribute to better decision making which will better affect services delivered to people. This view encompasses consumerism and accountability rhetoric (Health Canada 2000;HeBE 2002;Ridley and Jones 2002). There is a third motivation for participation and that is for the purpose of increased legitimacy and credibility of decision making. Linked to this is the vested interest in maintaining the status quo by bolstering existing decision making mechanisms (Harrison and Mort 1998b;Rowe and Shepherd 2002). While the following motivations are not mutually exclusive they distinguish different purposes for promoting community involvement in health care decision making. I have expanded on these areas below; ideology; a means to improve health and services and; a means to maintain or bolster traditional decision making processes.

For Jewkes and Murcott (1998) the purpose for deciding to involve public or community is all important. They found that the involvement of local groups and people on steering groups

proved a limited means of increasing democracy in health and in giving opportunities for community control. It did not result in community priority setting and decision making. On the other hand they observed that if the purpose of involving lay people was to engage with people with a different perspective than service providers, then members from these community and voluntary groups would be very effective at fulfilling this role rather than been regarded as representatives from an idealised community.

Community involvement as ideology

Proponents of community participation/ involvement as an end in itself see it as beneficial or 'good' in principle. Undoubtedly there is a wholesome quality to the notion of community involvement that even the most sceptical find hard to resist (Morgan 2001).

As Harrison (1998) points out, being in favour of community involvement is a bit like being 'against a sin'. Morgan describes categorisation based on motivation: participation to encourage empowerment and participation as utilitarian effort by donors or governments to use community resources to offset the cost of providing a service (Morgan 2001). Cooke & Kothari (2001) make explicit the potential and real dangers of participation. Their book describes how participatory development can facilitate the unjust use of power. The fact that the authors were tentative in "coming out" and expressing their reservations about the 'wholesome' notion suggests self-censorship in the context of a dominant ideology. This they felt reflected:

> A tacit anxiety about the consequences of having to challenge a set of practices to which the major development institutions, powerful individuals within them, and perhaps most importantly people who are good friends of ours, are committed (Cooke and Kothari 2001)

A chapter in the same book highlights potential negative effects of work involving ideologically bound groups. Cooke identifies risks including 'group think' to show the dangers inherent in the consensus approach in groups of like-minded individuals. He suggests that that participatory development as an alternative to development through transfer of technology and modernisation might be a breeding ground for these side effects (Cooke 2001).

Ironically however the ideologies that rely on participation as a central tenet and as an 'end' in itself are more easily satisfied than those which see it as a 'means' of achieving other goals. In other words it is easier to show that people have participated than to show how their participation has influenced decision making or effected health and services. The irony is that the ideological position risks being satisfied with less and there for being co-opted or being used for legitimisation (Harrison and Mort 1998), than the view of participation as a means which is only satisfied with tangible benefits to services, health, satisfaction or needs identification.

The lay and clinical members of Primary Care Groups as much as managers saw the purpose of community involvement as a means of attaining other goals. These were to improve the quality of services provided (clinical governance), to legitimise decisions and develop local accountability (local governance) and to improve public health through education and empowerment (health improvement) (Rowe and Shepherd 2002). Views were consistent with the New Public Management (NPM) approach which regards involvement as a tool to make the service more responsive, rather than as a process of empowerment of users in the decision making process. In this respect the authors agree with Harrison (1998) and Morgan (2001) that public participation is used as a 'social technology of legitimisation' and to make services more cost effective(Harrison and Mort 1998;Morgan 2001). They note however, that as with the activist's approach described by Morgan, some nurses and social service members referred to the potential for empowerment (Rowe and Shepherd 2002).

How information is gathered to make services more responsive is also affected by ideology with the consumerist model emphasising market research and the community development approach emphasising participative methods designed not only to gather information and plan responses but to see the members of communities as the experts and to empower participants (Chambers 1997). The underlying philosophy of participative methods is that data collection is valued as a process of learning in an iterative and systematic way in and of itself, not merely as an activity for the product of information (Rifkin and Draper 2000).

Participative health needs assessments, in developed countries have been influenced by developments in Participative Action Research (PRA) in developing countries (Rifkin 2000). Health needs assessments using participatory mechanisms are often the starting point for

involving communities in identifying needs and being part of the response to those needs as can be seen from experiences in Edinburgh (Murray 1995). These participative methods are advocated in the WHO healthy cities initiative and by a wide range of community development practitioners and trainers in the health field in Ireland (Cairde, Community Action Network, Combat Poverty Agency). The history of participatory research (PR), or participatory action research (PAR) as it is also called, emerged from the theoretical constructs of people's participation and empowerment. Inspired by the educator Paolo Freire, its focus was to address problems of poverty and helplessness through linking research with empowering education and action. Rapid appraisals (recently known as participatory learning approaches (PLA) became popular almost at the same time, in the early 1980s in both the health and development fields (Rifkin and Draper 2000a). However these methods which see the researcher as facilitator rather than expert are not without their critics on the basis that control of the information rests still with the outsider. Mosse (Mosse 2001) presents an example where 'local need' was actually shaped by local perceptions of what the agency in question could realistically be expected to deliver. However Chambers sees these participatory methods as recognising the ability of poor people to carry out tasks previously carried out by experts, allowing learning spread by peer group rather than by top down professionals and allowing reversal of roles as experts are required to establish a rapport with locals (Rifkin and Draper 2000).

Community involvement to improve services

Crawford et al (2002) undertook a systematic review of involving patients in the planning and development of health care. They included papers that described involvement of patients as 'the active participation in the planning monitoring, and development of health services of patients, patient representatives and the wider public as potential patients'. Of the 337 studies found involving patients in the planning and development of health care only 12% described the effects of the initiatives. The effects of involvement on services included new or improved sources of information for patients, improved access and new services (e.g. advocacy initiatives to improve employment, complementary medicine and fertility treatments). Two reports described how involving patients led to the abandonment of proposals to close hospitals. Other effects included changes in staff attitudes in becoming more open to involvement. Some researchers raised concerns about involvement being used to legitimise decisions making and about the slowing up of the decision making process. Crawford

(Crawford 2002) concluded that though evidence supports the notion that involving patients has contributed to changes in the provision of services across a range of different settings, they found no evidence - base for the effects on use of services, quality of care, satisfaction, or health of patients. He cautions that this absence of evidence should not be taken as an absence of effect. Similarly Fudge et al (2008) found that the gains of involvement were harder to identify in terms of the impact on services. More evident were the personal gains for those involved: satisfaction of feeling 'listened to' by professionals, social opportunities of meeting others in a similar situation, and increased knowledge about stroke and services available.

Involvement in Primary Care through the community development (CD) approach assumes empowerment of participants (Crowleyet al. 2002;Crowley 2004a;Fisher, Neve, and Heritage 1999;Fisher 2009;Freakeet al. 1997;Smithies 2004). Authors supporting this approach show success in identifying and implementing a range of activities in health which are seen as positively addressing health concerns (Crowley, Green, Freake, and Drinkwater 2002;Smithies J and Webster 1998). However practical examples suggest interpretations of community development as centring on health professionals adopting a way of working with community groups which includes networking and positively discriminating community groups priorities (Crowley, Green, Freake, and Drinkwater 2002;Freake, Crowley, Steiner, and Drinkwater 1997). Through the community development approach to community involvement in Primary Care, new programmes have emerged and been funded by the state. Other results have included services being made appropriate for community members and access to marginalised groups improved (Crowley 2005a;Quirke, Sinclair, and Kevany 1994a).

It is thought that involving public in health services will highlight areas of the service that professionals have neglected followed by priority and resources given to these areas and improvements (Clough 2003). Kai and Drinkwater's book 'Primary Care in urban disadvantaged communities' collates learning from Primary Care practitioners. Case studies show community orientated approaches making 'real differences' for local communities (Drinkwater and Kai 2004). Smithies provides examples of a community health project in Waltham Forest and a Primary Care Team approach to community development in Wakefield to show how involvement of communities contributed to the development of better relationships and user-orientated service delivery (Smithies 2004).

Many of the methods used to inform a more responsive health system focus on the accurate and participatory assessment of people's needs and wants e.g. focus group discussions questionnaires interviews opinion surveys observation (Clough 2003;Jordan, Dowswell, Harrison, Lilford, and Mort 1998a)

Community involvement to influence decision making

Involving the public in *strategic* decision-making is hoped to lead to improvements at an organisational level. In developed countries community involvement for the mobilisation of resources for basic health services becomes less emphasised and involvement in decision making in health care becomes more important. Also the growth of what is perceived as popular demand for accountability in public expenditure in the major social movements is given more emphasis in the context of developed countries (Jewkes and Murcott 1998b).

In spite of the rhetoric about involvement as a means of influence for those traditionally without power, research suggests the enduring influence of health service managers and clinicians as opposed to patients and local communities in shaping health care priorities and service (Milewa, Dowswell, and harrison 2002). In practice, public involvement initiatives often fail to move beyond consultation to give the public a more active and direct role in shaping service development (Coulter and Ellins 2006;Jordan, Dowswell, Harrison, Lilford, and Mort 1998a). Some suggest that public involvement is thus used to inform decision makers, and not to devolve power to local communities (Rowe and Shepherd 2002). Table 2 below is summarises findings from an extensive review for the Picker institute, which aims to strengthen the voice of the service user in health matters. The table shows that while systematic reviews suggest that involvement can increase the public's awareness and knowledge of health services and can increase the self-confidence of participants, there is mixed evidence on its impact on delivery of services. There is some evidence of slowed down decision making and limited evidence of influence on decision making partly because control of decisions is retained by managerial staff (Coulter and Ellins 2006)

Pickard (2001) examined two aspects of lay involvement in Primary Care Groups (PCGs): lay board members' involvement and engagement of the PCG with the wider public. She concluded that during the first six months of their operation the lay voice was 'only faintly heard' in the PCG and their role in decision making was 'peripheral'. Contact with the public

took the form of informing rather than consulting. Interestingly, the majority of lay members responding were satisfied with the low rate of involvement in decision making. The study also noted the 'reluctance of people to be involved without a personal obvious interest'(Pickard and Smith 2001).

Table 2. Summarised findings from an extensive review for the Picker Institute(Coulter and Ellins 2006)

Outcome variables	**Current state of knowledge Consultation Methods**	**Patient participation groups and forums**	**Lay representation**	**Current state of knowledge Systematic reviews**
Patients knowledge and information recall	The process of hearing evidence and cross-examining witnesses in the citizens' jury method increases knowledge about health services.	Not known	Lay board members expected to gain knowledge of health service and organisational structure.	Public involvement provides opportunities for learning, and can lead to improved knowledge of health services.
Patients experience including communication and psychological outcomes	Lay public values consultation and/or participation in deliberative approaches. Evidence that citizens' juries can influence decisions taken about local services, but some participants concerned about representativeness of jury members.	Participants often enthusiastic, but can Cbecome disillusioned if they feel managers/professionals are not taking their views into account.	Participants commonly report lack of influence over decisions, and no evidence of devolved power to lay representatives.	People welcome opportunities for involvement, and these can increase participants' self-confidence, self-esteem and levels of social contact. Some evidence that employing mental health service users as case workers (or trainers of case workers) improves quality of life and social functioning among clients. Mixed evidence for impact of planning and delivery of services.
Health service utilisation and costs	Citizens' juries are a relatively expensive method of public involvement, and the impact is dependent on sufficient investment of time and resources.	Limited impact on organisational decision making, partly because control over decisions retained by managerial staff.	Some evidence of increased workloads for NHS managers	Some evidence that decision-making is slowed down. Staffing is generally the largest expenditure, but insufficient data to indicate cost-effectiveness. User involvement in the delivery of mental health services found to reduce hospital admissions, increase time between hospital visits and shorten duration of hospital stays.
Health behaviour and health status	Not known	Not known	Not known	Not known

Involvement to improve health

There are a number of arguments to support the idea that communities becoming involved in health decision making will improve health. One is that participative action with others in one's community promotes social cohesion. The second is that effecting influence or control in factors affecting one's life is empowering and associated with improved health.

The first of these is supported by a number of studies which link social cohesion with increased life expectancy. Links have been made between income differentials, social cohesion and mortality. Wilkinson shows that during the war in Britain the income differentials were compressed and greater social cohesions experienced as well as a rapid increase in life expectancy (Wilkinson 1996). Conversely in a close nit town in Pennsylvania during the 1960s rapid economic change, there was a widening of the gap between rich and poor with a resultant change in community cohesion followed by an increase in deaths from coronary heart disease. Socially Isolated people die at two-three times the rate of well-connected people (Kawachi, Kennedy, and Lockner 1997). In 1995, Berkman reviewed population based research on mortality risk over 20 years and found that people who are isolated are at increased mortality risk (Berkman 1995). She recommended interventions targeted at high risk populations to promote social support as well as family and community strengths. Putman measured social cohesion / capital by the density of citizens' participation in community organisations (choral societies, soccer leagues, Rotary clubs). He found that social capital not only increased the likelihood that citizens were more likely to trust their fellow citizen but also to value solidarity equality and mutual tolerance(Putman 2000). Kawachi et al correlated civic trust and density of associational life in 39 states in the US and found that civic distrust and paucity of associational life were strongly correlated with increased overall mortality. They concluded that the effect of income inequality on mortality seemed to be mediated through withering social capital (Kawachi, Kennedy, and Lockner 1997).

The second argument is that involvement in decisions is integral to notions of empowerment by which people gain control over factors affecting their lives. There is some evidence that the more control we have over decisions that affect us the better our health and wellbeing. Bosma (1997) conducted a study to test the hypothesis that psychosocial factors, particularly related to work, may be important in the generation of the inverse social gradient in mortality from coronary heart disease (CHD) in the Whitehall study of British civil servants. In Whitehall II the

specific psychosocial work characteristic of low control made an important contribution to the social gradient in incident CHD in men and women (Bosmaet al. 1997). Similarly in 2000 Cheng et al in a study of over 21000 female nurses found that low job control, high demand and low social support was associated with poor health outcomes (Chenget al. 2000).

While the achievement of people's empowerment through involvement is difficult to prove empirically, reports of positive feelings as a result of participation are common. Simpson and O' House reviewed comparative studies which involved users of mental health services as employees, trainers and researchers. They found that involving users with severe mental disorders in the delivery and evaluation of services was feasible and was associated with positive attitudes of users and providers(Simpson and O'House 2002). A synthesis of findings from 12 research projects in the UK department of health 'health in partnership programme' showed that public involvement i) increases the confidence, understanding and skills of the people who participate, ii) influences the policies, plans and services of Primary Care iii) organisations iv) enable learning, resources and expertise to be shared across health economies (Farrell 2004).

While evidence exists for increased control in the workplace and better health outcomes has been shown in these empirical studies, there is an assumption that participation in health leads to control. In practice there is limited empirical evidence to demonstrate that community involvement / participation contributes to better quality healthcare (Simces 2003). Nevertheless, because there is a dearth of empirical evidence does not mean that involvement in the decision-making process is not good for one's health. Researchers are at pains to make this point (Coulter 2006).

Involvement as an opportunity - according to interests

The benefits of community involvement or participation can be categorised by the interests of those who are calling for the participation. The benefits to government including: the removal its responsibility for people's health; potentially increasing effectiveness of services as well as; cost sharing with the communities (Morgan 2001;Navaro 2002;Oakley 1998;Rifkin and Draper 2000). Some authors believe that this is suggesting that the emphasis on community participation for mobilising resources reflects the idea that Primary Health Care could be done 'on the cheap' (Foster 1982).

Professional interests have been seen as a barrier to community involvement and GPs have been seen to resist patient involvement (Jones, Berney, Kelly, Doyal, Griffiths, Feder, Hillier, Rowlands, and Curtis 2004a). Brown (2001) found that General Practice was orientated towards a narrow medical role and associated with a low valuation of involvement. He found that power was a critical issue 'with evidence in the study of the dominance of the medical practitioners in establishing organizational values and the nature of public involvement activities'. He concluded that a change in culture in general practice would be essential if public involvement is to be more than superficial window dressing (Brown 2001).

Types of involvement

In accepting involvement as a process (whether a means or an end or both), several authors have endeavoured to articulate levels of that process. Their objective has been both to promote clarity in thinking about involvement as well as promote the ideology itself. Their methods can be distinguished in various ways, but are often expressed in hierarchical forms identifying the extent to which they seek to empower people and democratise the decision-making process (Coulter and Ellins 2006;Rowe and Shepherd 2002).

Typologies have considered involvement of different groupings (individual to collective) as well as considering the level or depth of involvement e.g. from experiencing a service to controlling it (Brown 1994c). Others have included definitions which are based on the relationship with the service (service user, patient, survivor). The range and potential of meaning and implication is described in a review of patient and public involvement (Simces 2003) as follows:

The intent or meaning could range from individuals having a greater say in managing their own health care, to involving the public in the planning and development of health care, to involving citizens in local health authorities or in defining values for the health care system.

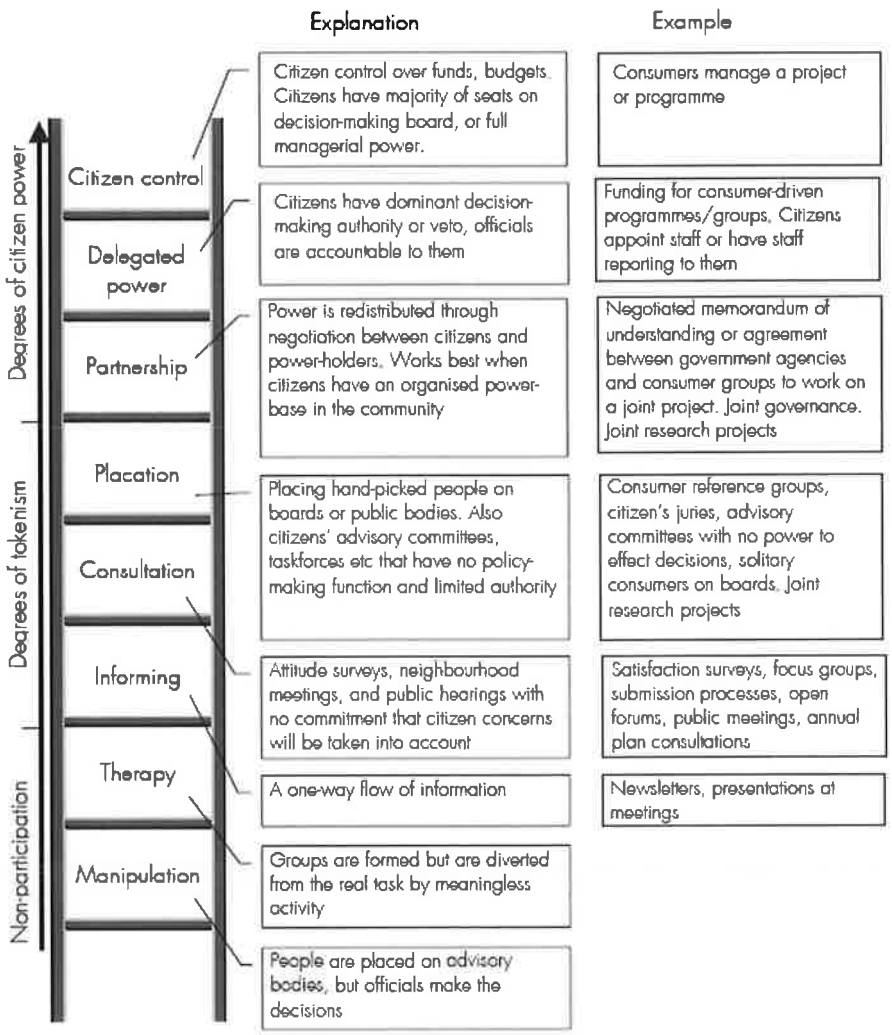
The main distinction between 'consultation' and 'participation' was seen as the degree to which those involved in the process are allowed to influence, share, or control decision-making.

A multitude of approaches to community involvement and people's participation emerged in response to Alma-Ata's call for Primary Health Care (Zakus and Lysack 1998). As far back as

1986, Rifkin described approaches to participation found in health projects. She identified three types of approaches i) the medical model ii) the health planning approach and iii) the community development approach. The medical model approach argues that through applying medical knowledge advances in science and technology disease can be combated in large groups. This approach sees community participation as communities responding to professional direction and expects that through increased knowledge and professional guidance people will take action to improve their health. The health planning approach sees health improvement as being rooted in the appropriate delivery of services which can only be done through consultation and contribution from community. These two approaches are 'top down' with the professional providing content and direction. The last type is 'bottom up' and community directed and sees health as a human condition not a result of the availability of services. According to this approach people have a right and duty to be involved in decisions that affect their lives (Rifkin 1986).

The most cited model of participation was developed by Arnstein in 1969 to describe levels of citizen participation from information through consultation to transfer of power (Figure 2). Arnstein suggests that consultation is merely 'a pretence' if it is not combined with other methods, as it is unable to ensure that the concerns and ideas of those consulted will be taken into account (Arnstein 1969). Arnstein's typology is quite simplistic but usefully presents a number of elements to the developmental process of participation. Moreover, it has become a standard reference point in the literature on service user consultation and participation (McEvoy, Keenaghan, and Murray 2008).

Figure 2 Arnstein's ladder of citizen participation



Source: (Coney 2004)

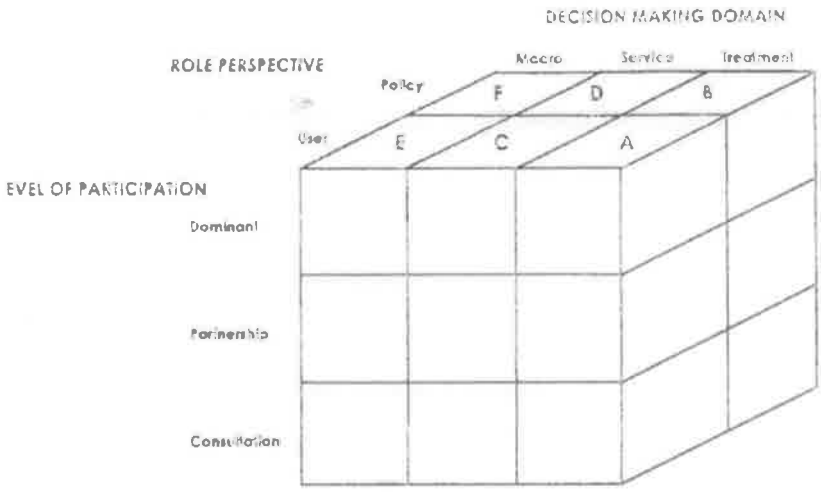
Other models have used Arnstein, either collapsing or changing her levels to show increasing levels of public or citizen involvement. Some have omitted the first two steps because they have been considered as non-participation (HeBE 2002).

The stepwise categorisation of participation infers not only levels of participation but also progression in an up down movement: up being deemed as good and down as bad. However more complex classifications involve matrices with two and more variables (Jordan, Dowswell, Harrison, Lilford, and Mort 1998a). Peck et al for example draw on Pilgrim & Rogers classification which describes people with disabilities according to their relationship with the health service i.e. as patient/consumer/survivor (Pilgrim and Rogers 1993). They then include Hirschman's (Hirschman 1970) idea of participants' reaction to services i.e. loyalty, voice, exit.

They then use a collapsed version of Arnstein's model to develop a matrix with the *conceptions* of user involvement forming one axis and the *levels* of user involvement forming the other (Peck, Gulliver, and Towel 2002).

Charles and DeMaio develop a framework of 'Lay participation'. They identify three dimensions: level, role perspective and decision making. Level draws on Arnstein collapsed into 3 groups; consultation, partnership and dominant. 'Role perspective' is divided into two groups i) that of a user of health services and ii) a public policy perspective. The decision making domain is divided into three sub-domains to distinguish treatment, services delivery and broad macro or systems level decision making contexts. When these three domains are combined they create a three dimensional framework or matrix (Figure 3). The framework can be used to clarify expectations and so avoid dissatisfaction of those involved (Charles and DeMaio 1993).

Figure 3. Charles and DeMaio's three dimensional framework for lay participation

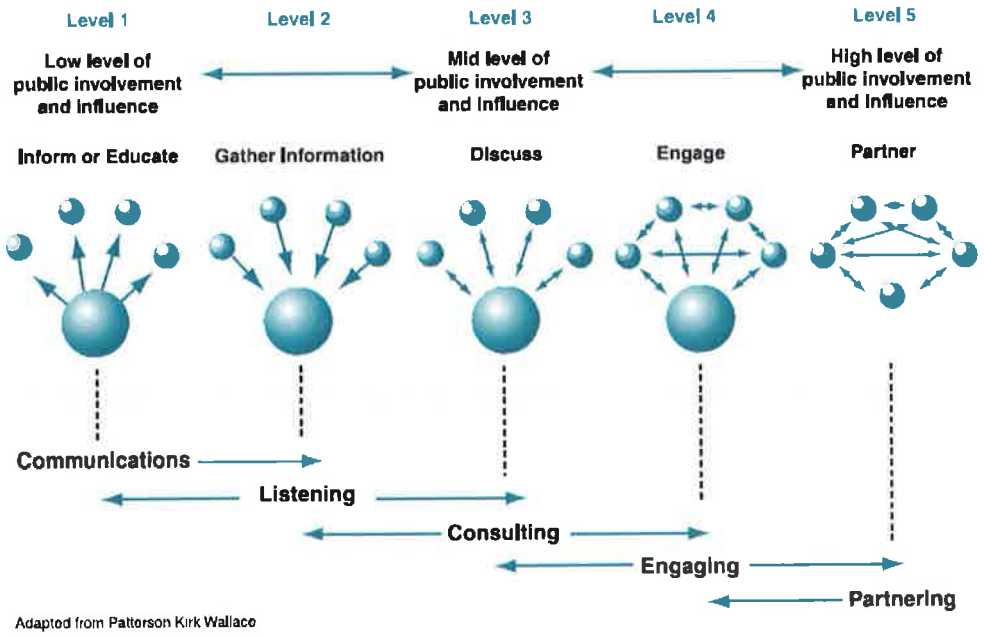


Source (Charles and DeMaio 1993)

More recently Health Canada (2000), devised public involvement on a continuum (Figure 4), with five levels of public involvement and influence identified. They stipulate that the levels are not "air-tight" compartments but are generally cumulative as the public involvement deepens. This typology ignores the first to levels of Arnstein and begins at the provision of information the high end of the involvement continuum. The authors give the example of the

response to the Sydney Tar Ponds contaminants issue in Cape Breton, Nova Scotia as an example which illustrates a community based citizen engagement model at the partnership end of the public involvement continuum. This controversial health and environmental matter is addressed through a community-driven process, in which the government is invited to participate – rather than a government-led process in which the community participates. The authors conclude that citizen engagement refers to the public's involvement in determining how a society steers itself, makes decisions on major public policy issues and delivers programmes for the benefit of people (Health Canada 2000)

Figure 4. Health Canada's Public involvement Continuum



Source (Health Canada 2000)

Table 3 below displays WHO defined levels of community participation along similar lines as Arnstein. In this typology we see people having seats on boards with no power is classified as manipulative participation. The other end of the spectrum is 'self mobilisation' where people take initiatives independent of external institutions to change system/situation.

Table 3. Levels of community participation (WHO 2001)

Type of participation	Key Elements
Manipulative participation	Participation is a pretence – people's representatives are on official boards but have no real power.
Passive participation	People 'participate' insofar as being told what is going to happen or what has already happened. A unilateral announcement may be made by an outside agency, and people's responses are not taken into account.
Participation by consultation	People are consulted. External agencies define both problems and information gathering processes. Such a process does not concede a share in decision making and professionals are under no obligation to consider people's views in designing interventions.
Participation by material incentives	People participate by providing resources e.g. their time or labour, in return for food, cash or other material incentive
Functional participation	People participate by forming groups to meet pre-determined objectives related to the project. Such involvement tends to occur after major decisions have been made.
Interactive participation	People participate in joint analysis of problems, which leads to action plans and the formation of new local groups or the strengthening of existing ones. These groups take control over local decisions, and so people have a stake in being involved.
Self-mobilisation	People participate by taking initiatives independent of external institutions to change system/situation.

Source (World Health Organisation 2001)

Involvement through Groups and forums

Harrison & Mort (1998) examined two practices: public consultations through health panels, including citizen juries, and user involvement where a group of people were selected to represent their community as a whole. The concept of health panels involves the revisiting of the 'general public' over time. These panels were considered 'representative' groups of citizens in terms of their characteristics. The study showed that despite the engagement of a significant number of health authorities in public consultation through health panels, none agreed to be bound by their decisions:

Despite the positive attitudes of health and social services managers and professionals all were careful to leave themselves with the ammunition to ignore the outcomes of 'user involvement' and many were able to use it for their own internal political purposes.

Professional and managerial responses to user groups showed that these groups were simultaneously constructed with legitimacy by positive expressions about them and deconstructed by reference to their representation (Harrison and Mort 1998b).

Involvement through Lay representation

Crawford et al (2003) identified three forms of representation: democratic, statistical and typical. Democratic representatives must represent the views and interests of those who elected them. Statistical representation means that the characteristics of the general population are reflected. Typical representatives must have a shared set of experiences with a particular group of people (e.g. users of a particular health service). Legitimacy is called into question if lay participants are felt to represent only a select group or to have strong personal agendas. Concerns about the 'representativeness' of those who contribute to public involvement initiatives are well-documented as a barrier to successful public involvement (Crawfordet al. 2003). Others have questioned the importance of 'representativeness' and seen it as a mechanism to discredit a position they did not agree with or to prevent inclusiveness and diversity (Coulter and Ellins 2006;Crowley 2004a). However including the excluded is a considered a challenge frustrated by obstacles such as language difficulties, cultural differences, learning and physical disabilities, caring responsibilities and poor mobility (Lockey and Hart 2004). Marginalised groups are often at a disadvantage because they of their marginalised position and may not possess the luxury in time, commitment, energy, belief, and importantly access and understanding of management discourse and practice to allow participation (Rutteret al. 2004). Furthermore marginalised communities may not be willing participants (Bandesha and Litva 2005).

Alborz (2002) found single lay members on professionally dominated Primary Care Group boards content with their fairly limited involvement. Alborz used data from 15% of the Primary Care Groups or Trusts (PCG/T) in England to show that though most PCG/Ts had public involvement in working groups, a minority of chairs felt that consultation was effective. She concluded that efforts to involve the public may become little more than token gestures. Though the UK government proposal for new PCT to have a lay majority was welcomed the authors note:

..the professional executives of PCTs are not required to hold their meetings in public, thus effectively removing the opportunity for public scrutiny of the decision-making process (Alborz, Wilkin, and Smith 2002).

Brown (2001) surveyed GP organisations and found only a small minority of general practice teams had undertaken activities to involve the public (Brown 2000). He found;
.. an orientation to a narrow medical role and to general practice as a business are associated with a low valuation of involvement; an orientation to teamwork and to a broader social role appear more congruent with the development of involvement.

He concluded that power was a critical issue and evidence of the dominance of the medical practitioners in establishing organizational values and the nature of public involvement activities (Brown 2001) .

Local decision makers have displayed scepticism about the extent of demand for participation. This attitude reflects that of a growing body of literature which emphasises the importance of not simply assuming that public involvement is a "good thing" and stresses the need to identify the extent to which the public wish to be involved in decision making (Rowe and Shepherd 2002;Wistow and Barnes 1993).

Experience of community involvement in health in developing countries

The WHO study group on community involvement in health warned that while the rhetoric is high 'the talk has not been put effectively into action' (WHO 1991). Two case studies for each of eight Latin American and Caribbean countries were reviewed and levels and type of participation occurring described (PAHO 1984).

Most of the health systems in the countries studied followed a typical PHC model of increasingly complex levels of health services, with the most basic PHC services at the community level and two or more referral levels. Almost all the countries indicated that they had a national policy supportive of community participation. Three distinct levels of participation were defined:

- Utilisation of services and facilities provided,
- Co-operation with initiatives planned by an outside agency and
- Involvement in planning and managing activities.

  The term 'involvement' was used as the highest form of participation and the authors contest this is usually what is meant by 'community participation' (PAHO 1984).

About half of the case studies reported some degree of community involvement. In Barbados while the community was very active in other sectors there was little community participation in health. The system had not implemented its community participation policy and there was no mechanism to link the health system with the community except for the direct provision of services. The health needs appeared to be adequately met: there was no perceived need on the part of either the system or the community for the community to take any action and both shared the perception that health is primarily a government responsibility. On the other hand in Cuba the reviewers attributed the reported level of community involvement to the social system. There was a solid organisational base on which the health system was stood providing channels for participation and training of health personnel and community representatives. The case studies gave little detail on the effects of Community Participation on broader objectives. In general the cases with a greater degree of involvement also reported more impact of community participation on coverage programme, effectiveness and social conditions (PAHO 1989). The authors acknowledge that it is difficult to attribute causality because of the multiplicity of variables and intervening factors.

But evaluators differ, Morgan's (1993) analysis of Cuba's experience of community participation with health, conflicts with the PAHO view. She sees poor participation in the Cuban experience for the same reason as the PAHO see it as successful i.e. the political structure. Morgan suggests that the judgement of success or failure tells more about the political convictions of the evaluator than it does about the programme. She concludes that, ..analysis of the struggle for and against 'participation' are struggles about social stratification and the distributions of and control over political and economic resources within a society (Morgan 1993a).

In her political economic ethnography of community participation in health Morgan draws the paradoxical picture of 'conventional participation' which is state defined 'managed participation' in accordance with international guidelines as opposed to 'non-conventional participation' whereby people mobilise against the government in strike action, demonstrations, and revolt. Morgan describes 'participation' as a political symbol and the World Health Organisation as being motivated by a political commitment to democracy as the path to social equity. She notes that the organisation decided 'a priori that community participation would be a component of Primary Health Care'.

The very existence of a distinction between 'conventional' and 'unconventional' for Morgan demonstrates the state's hegemony over the concept of participation. The UN she argues contributed to increasing state control over community participation.

Government sponsored top down participation is for some a contradiction in terms and successful participation is that which is not sponsored by government. White (2000) points out there may be an inherent paradox in 'invitations to be involved':

Community participation has been invited if not invented by those very administrators who are now central to the system. This means that insiders determine the rules and structures through which outsiders can approach the decision making arenas as well as the resources to which they have access, once there (White 2000a).

Morgan finds decreasing participation with increasing state involvement and explains this by stating that increased participation is simply unnecessary and unwarranted where relations between state and citizen are more cooperative and mutually respectful or 'where the citizens are the state' (Morgan 1993a).

In evaluating community involvement in health it is necessary to look at the successes of comprehensive PHC as the concepts are so similar. The PHC programmes which have been successful have often been small scale and with charismatic leaders notably Jamkhed in India which provided evidence for the value of community health workers (CHWs) and a community development approach to health (Bhatia and Rifkin 2010). National evidence is more limited. Though many experts call for a revitalisation of PHC(Commission on the Social Determinants of Health 2008;World Health Organisation 2008), Bhatia and Rifkin point out that the world is a different place now than it was when PHC was developed and therefor rethinking about and reframing of PHC is needed (Bhatia and Rifkin 2010a).

Experience of community involvement in health in industrialised countries

Much of the emphasis on participation and involvement in health care in North America Australia and Europe stems from a consumerist perspective. Delaney et al (2002) trace the development of the patient and public participation in the USA from an emphasis on the development of patient rights in the sixties and seventies, to court cases in the eighties confirming the authority of the patient and families in deciding issues of medical treatment, to concern in the growing costs of health care for patients in the 90s. This led to increase focus on evaluation outcomes and consumer satisfaction.

The focus on patient and public involvement as a single or collapsed concept has been the approach in many industrialised nations in the nineties and early 2000s. Initially involvement tended to be at the level of looking for feedback. Emphasis on professionals working in partnership in the eighties and developing overall consumer strategies in ad hoc projects were a focus of the nineties, with more recent efforts focusing on engaging citizens and the public for the purpose of priority setting decision making and rationing (Delaney, Keegan, and McGee 2002b).

Butler et al. (1999) indicate that Australians tend to take a passive role with participation in the political sphere, with a 'them and us' perception of the relationship between government and community. She says that health issues tend to be thought about in terms of 'what will government do about it'. Government is seen as having a great deal of control over health decisions and expenditures. In comparison to a number of western countries, and some notable exceptions, the Australian people have relatively good access to health services, through Medicare, and inequities in health status are generally less visible in the community. As a result, there may be fewer reasons for individuals to join groups to improve or change health services.

Charles and De Maio (1993) placing lay participation in Canada in its historical context describe a health reform context in the 1970s where they quote Foulkes as saying "..in the existing 'non system' the consumer had been ignored" (Foulkes 1973). The suggested solution to the fragmented, uncoordinated and piecemeal development of the health care services was a rationalisation of the system to create an integrated system. Public participation in health care decision making was a secondary and more minor issue to the fallout from the dominant organisational reform (Charles and DeMaio 1993).

In 1994 the National Health Forum (1997, final report) was established to involve and inform Canadians, and to advise the Federal Government on innovative ways to improve the health system. One of Canada's most comprehensive examples of citizen engagement in health care planning is the Commission of the Future of Health Care in Canada (Romanow 2002a;Romanow 2002b). This is based on the premise that, the 'judgement and values of Canadian's perceptions of the national health care system need to be understood'. The Commission implemented an extensive process to provide Canadians with a better understanding of the challenges confronting publicly funded health care, as well as choices and options available to them (Simces 2003).

Partnership and the increased involvement of patients in the UK have been goals of the UK NHS for a number of years (Delaney, Keegan, and McGee 2002b;Department of Health 2000;Department of Health 2001). Mental health service users were the first to organise in England in the 1970s. The results of the Inquiry into the management of the care of children receiving complex cardiac surgery at the Bristol Royal Infirmary between1984-1995 called for a

national body to represent the public's interest. It concluded that the public's interest needs to be embedded into all the organizations and institutions concerned with quality of performance within the National Health Service (NHS). This led to the establishment of a Commission for Patient and Public Involvement, which is a legislated government body that explicitly mandates consumer participation in policy, program and legislative processes (Farrell 2004b). Since then service user activism has taken many forms: through patient councils groups exploring the meaning of 'Hearing voices' groups promoting complementary therapies and direct action (Peck, Gulliver, and Towel 2002). Policy commitments relating to participation including 'Shifting the balance of power' acknowledged the disempowered status of patients and to some extent the failure of what went before. The NHS Plan announced;

For the first time patients will have a real say in the NHS. They will have new powers and more influence over the way the NHS works (Department of Health 2000)

A key aspect of public involvement is the duty which was placed by Section 11 of the Health and Social Care Act 2001 on Primary Care Trusts and NHS Trusts and Strategic Health authorities to make arrangements to involve and consult patients and the public (Govenment of UK 2001). The establishment of Primary Care Groups in the UK was the first systematic attempt to introduce local opinion into decision making processes in Primary Care (Anderson 2006).

Since 2001 the NHS multi-sectoral partnership working is promoted in new service planning and delivery organisations (PCGs , PCTs) as a core operating principle (Brown 2001;Coulter and Ellins 2006;Milewa, Dowswell, and harrison 2002). The new political development of the NHS since 1997 in line with 'the third way' philosophy arose as an alternative to the consumerist or citizenship model. This changed health planning discourse with words like 'community' and 'partnership' replacing words like 'markets' and 'contracts'(Pickard and Smith 2001).

In 2001 in response a National Listening Exercise, the Department of Health (2001) published a package of measures for involving patients and the public in Health Care (Department of Health 2001). This builds on a long line of attempts to include the views of the public from Community Health Councils (CHCs) and patient groups in the seventies to Patients' and Public involvement Forums and Patient Advice and Liaison Services (PALS) in the 2000s. The

Commission for Patient and Public Involvement in Health (CPPIH) was established in January 2003 to set up and support Patients' Forums. This independent, non-departmental public body (NDPB) was abolished on the 31st March 2008 when Patient Forums were replaced by Local Involvement Networks (LINks)(Department of Health 2008). Local Involvement Networks (LINks) aim to give citizens a stronger voice in how their health and social care services are delivered. Run by local individuals and groups and independently supported - the role of LINks is to find out what people want, monitor local services and to use their powers to hold them to account (Department of Health 2010). These developments show that involvement of patients and the public in health decision-making is now a central theme of national and local policy in the NHS (Coulter and Ellins 2006;Farrell 2004).

Delaney et al describe the recent status of the Northern Ireland, Scotland and Wales strategies on community involvement in health. Scotland's strategy document in 2000 appears to be the start of the process of involvement with a commitment to 'Involve people and communities in the design and delivery of the health services'. This early stage strategy emphasises communication, information and training for health care staff. The Welsh plan sees involvement as an ideology and acknowledges the need for management changes in the NHS before involvement of patient can be achieved. The plan emphasises transparency around the extent to which patients and the public are involved in decision which affect their care. The Northern Irish strategic plan also acknowledges the need for increased participation. Here the community development model has informed some of the initiatives. The need for resources to increase community capacity and skills in order to act as equal partners is identified(Delaney, Keegan, and McGee 2002).

The OECD published a report based on the previous two year findings from extensive surveys, meetings and case studies of OECD member countries (Organisation for Economic Co-operation and Development (OECD) 2001). This has shown that while all countries have increased efforts to inform and communicate with citizens "active participation and engagement of citizens in decision-and policy-making is rare, and restricted to a small number of OECD member countries". Government initiatives to seek more citizen input are relatively recent. Depending on the political or social context, the rationale for increased public participation reflect different priorities, such as strengthening democracy (e.g. Norway), enhancing transparency and accountability (e.g.Korea, Italy) or achieving better service

delivery (e.g. Australia, New Zealand, Spain, the United Kingdom). Canada has identified all three priorities in developing Public Involvement and Citizen Engagement strategies (Simces 2003).

Experience of community involvement in Primary Care in Ireland

Prior to the Primary Care strategy there were few examples in the literature of community involvement in health in Ireland. Those that did appear were often influenced by returning development workers (McCabe and Keyes 2005;Murphy 1999;Quirke, Sinclair, and Kevany 1994). Most notable among these is the Primary Health Care project for Travellers which uses the community development approach to train Traveller women as community health care workers. The project which increased access to health care for travellers as well as the range and appropriateness of services has been replicated in other areas. In 2005 there were 25 such projects nationally (McCabe and Keyes 2005)

Besides these isolated examples community involvement in the health system was treated as something of an 'add on'(Deane 2004b). In 2003 and 2004 the Irish Department of Health and Children funded 31 groups and initiatives to explore the links between poverty and health inequalities (CLES consulting 2008). As part of this four projects aimed to develop community involvement in Primary Care using a community development approach (Crowley 2005). The review does not evaluate outcomes but gives a running update. It appears that the Lifford Clonleigh experience (case 1 appendix VI) was considered the most successful having achieved lay representation on the Primary Care team and the establishment of a Community Health Forum. However concerns were raised about sustainability if state funding was discontinued. This dependent approach also raises both questions about the ability of the community to effectively challenge the authorities they rely on as well as the sustainability of participation. The health needs assessment approach in case 2 (appendix VI) is a recognised way to initially engage community participation and interest in health. However this project raised concern by the Primary Care Team about raising 'community expectation' which they felt they may not be able to meet. The Fatima community (case 3 appendix VI) appeared to want an alternative health centre (i.e. outside the Primary Care team's remit). In Mulhuddart case 4 (appendix VI) funding produced an analysis of health in the area which was used to help community groups lobby for better services (Crowley 2005b).

Evaluateors of the second phase of the Combat Poverty Agency (CPA) 'building healthy communities' programme found that capacity was enhanced among participants and projects involved. Programme participants reported that the programme had helped them build and develop effective relationships with national and government organisations. It also found that geographic communities experienced 'positive health outcomes' as a result of the project, though it countered that these were not easy to measure. Health outcomes were based on how those involved felt as a result of involvement. The report notes people became aware of own health condition and the social determinants of health. The role of the community health worker was found to be an important aspect of the projects particularly in the area-based initiatives (Lynam 2007;CLES consulting 2008).

The evaluation also claimed that the programme succeeded in developing and implementing mechanisms for effective community participation in health decision-making. However evidence that decision-making had been influenced was not provided. As with many evaluation of participation indicators were of process rather than outcome based (e. g. improved engagement and dialogue between groups and professionals and policy makers and submissions made by projects on policy issues). The results of submissions and engagements in terms of changes or new health services were not provided by the evaluators. Impact of the project appears to be assumed, for example the evaluation states that 'improved voice gave senior decision-makers a chance to hear about how health policy affected disadvantaged communities and the issues', but does not provide evidence of change as a result of this.

As well as failing to measure outcome neither evaluation was entirely independent. The CPA remit was to support community development approaches and so it had a vested interest in showing that this was a successful approach to tackling health inequalities. As Morgan points out; evaluations of the judgement of success or failure of participation tells more about the political convictions of the evaluator than it does about the programme (Morgan 1993). These evaluations do confirm however the form of community development supported by the CPA is the collaborative type rather than the radical or confrontational type which Morgan (1993) describes. This is not surprising as it would be difficult to independently challenge government while being funded by it.

Section Summary

The motivation to involve community and public can also be seen as a *means* to improve services or health status or an *end* in itself (Coulter and Ellins 2006;Oakley 1998;Rifkin and Draper 2000a). While there is some evidence that participation and involvement is good for participants' self-esteem and empowerment (Simpson 2002), there has been limited empirical evidence to show that community involvement in health care planning and decision making improves healthcare, health outcomes or quality of service (Coulter and Ellins 2006;Simces 2003), with a minority of studies describing the effects of the involvement initiatives (Crawford 2002). Many studies reported that involvement strategies had little overall impact on the decisions that were taken about service development (Coulter and Ellins 2006;Crawford 2002;Harrison and Mort 1998b;Pickard and Smith 2001;Rowe and Shepherd 2002). Author are keen to point out that the lack of evidence should not be seen as a lack of effect (Coulter and Ellins 2006)

Attempts at clarifying exactly what it means has led to categorising types and levels of involvement. These attempts value citizen control over state control of decision-making. Typologies attempt to drive out some of the ambiguity surrounding involvement as well as identify levels of involvement. Typologies that include unintended consequences such as 'tokenism' or 'manipulation' allow these types of participation to be made explicit. Typologies implicitly or explicitly include dimensions of power over decision-making as well as notions of relationship.

In the context of developing countries participation has been seen as part of comprehensive Primary Health Care. The PHC programmes which have been successful have often been small scale and with charismatic leaders while national evidence is more limited (Bhatia and Rifkin 2010a). In developed countries there have been increased efforts to inform and communicate with citizens, nevertheless active participation and engagement of citizens in decision making is rare. In Ireland besides some notable models of Primary Health Care for particular groups (Travellers) community involvement in health has been seen as an add on in formal health services. Recent efforts have been made to encourage participation through the community development model.

Conclusions

There are conceptual differences between Primary Health Care and Primary Care which are based on the centrality of community and the degree to which social determinants of poor health are tackled (Bhatia and Rifkin 2010;Deane 2004;Hannay, Sunners, and Platta 1997;Macdonald 1992; Starfield 1992).

Views on participation and involvement are dependent on ideologies and whether people are seen as consumers or citizens. The two do not sit well together. The former favours the individual needs and the latter sees the person with rights as well as responsibilities and part of a collective. Consumerist ideology gives rise to types of involvement which aim to improve satisfaction with commodities while citizenship models favour control over decision making. The literature agrees that meaningful involvement includes influence on decision.

Notions of opening decision making spaces for others to have a say will always have a power dimension as can be seen by typologies examined to aid in the evaluation of involvement strategies. Cornwall's typology described in the introduction allows for spaces to be identified and categorised where these power dynamics can be examined. However an attractive aspect of Cornwall's spatial way of thinking about participation is that it allows spaces be created where they do not exist or leveraged open where they are closed tight (Cornwall 2002;Cornwall 2004). Once spaces are categorised power dynamic are made easier to determine.

Through the literature the recurring theme of power emerges with PHC being thought by some as challenging medical power and by others as not going far enough to radically challenge the unequal distributions of global wealth. Supporters of the latter view see PHC as a hegemonic solution put forward by the dominant classes or as poor medicine for poor people.

While most acknowledge the influence of the PHC movement on the Primary Care model in developed countries the two models share less than they do not. Though both concentrate on catering for the least serious illnesses among the biggest part of the population they are built on very different principles and aim to respond to very different problems in very different environments.

Nevertheless forms of participation in health care particularly for deprived areas often utilise models associated with the PHC movement and the social determinants of health. Ireland is no different here, having a long and strong history of state funded community development particularly in areas of deprivation. More recently with the formalisation of the PC strategy community development is being called upon to deliver the participation requirement.

The other running theme in throughout the literature is the paradox that lies beneath some of the central concepts, and how they are applied such as government sponsored involvement, forced participation and externally stimulated community development (Hickey and Mohan 2004;Morgan 1993)

Chapter 3 Methodology

'To perpetually question the obvious and the very frames of civic debate so as to give ourselves the chance to think the world, rather than being thought by it, to take apart and understand its mechanisms and thus re-appropriate it intellectually and materially' (Wacquant 2004)

The Natural history of this research

Three General Practitioners (GPs); PC, AOC and DW came together with an idea. PC had the idea in the first place, having returned to Ireland from Newcastle where he worked as a community worker bringing together communities and the formal health system. He had been inspired by his experience in Nicaragua where he worked for five years and had seen the power of people's participation. PC was a 'believer' in the community development ideology that helped communities identify health needs and influence services (Crowley 2004b). He believed that Primary Care (which he saw as General Practice) in Ireland could benefit from community involvement through this approach. Returning to Ireland, PC began practicing as a GP in AOC's Family Practice. AOC was at this time developing a reputation in Dublin for working with socially marginalised groups (asylum seekers, homeless and drug users). AOC was also at this time a serving member of the North Inner City Partnership in Primary Care (NICP). He was involved in GP training in the Royal College of Surgeons Ireland where he met DW a senior lecturer with a strong research record. They all agreed to look for funding and a research student in order to put PCs idea into practice. A proposal was written by the three to develop and evaluate mechanisms to involve community in Primary Care. PC was keen to show that community development was an effective model to do this. The plan was to create engagement between NICP and 'community' to see if a common health agenda could be devised and acted on. I was to implement this plan as well as monitor and evaluates it. A Steering group was established with the GPs the Chair of the Inner City Organisations Network (ICON) and the coordinator of the NICP in Primary Care, to oversee the project

Enter me.

I, like PC had spent a number of years overseas. Having qualified as a nurse I worked as a humanitarian aid worker in Africa for 5 years. However I steered away from long term community development (CD) programmes finding the privileged position as the 'expert

outsider' facilitating communities to develop, a little uncomfortable. I think it fair to describe myself as a sceptical activist. I have consistently tried to make changes for people who experience social injustices and marginalisation remaining sceptical that big changes in the structure of society would result. Basically I take the side of those who I *perceive* as the underdog, generally in terms of power. In the first part of my career I endeavoured to challenge social injustices through action, in the latter part I try to understand and challenge them. I am sceptical about that which does not make logical sense to me and have problems 'believing' in movements or religions. I do believe however in fighting for those who cannot, for whatever reason, fight for justice themselves or who need an extra pair of hands to even the odds.

On becoming acquainted with the three GPs and their idea, I had difficulties understanding what was involved but felt it was my own lack of knowledge around the key concepts rather than any inherent problems with the concepts or feasibility of the project. I set about immersing myself in the literature surrounding the central concepts inherent in the research question.

The methodological bases of ethnography

The methodology for the subject matter of this research project had been more or less decided at the time I engaged with it. I found I liked what I read about ethnography as it fit with some of my theoretical assumptions; for example that it produces a situated knowledge rather than universals. Like Wolcott (Hammersley and Atkinson 1983), I see ethnography as not simply a set of methods but a perspective or a style of research that is distinguished by its objectives; to understand social meanings and activities in a given setting or settings (Brewer 2000). The aim is to reduce distortion and bias and maximise accuracy acknowledging that pure objectivity is not possible (Hammersley and Atkinson 1983;Silverman 2000). There are different kinds of methodological frameworks in which ethnography is located that are based on responses to the natural science critique: defence of the natural science model (scientific or positivist ethnography), rejecting it (humanistic ethnography) and transcending it (postmodern reflexive ethnography). Postmodern ethnography criticises the claim that ethnography is a privileged method (humanist) while this view requires that ethnography is rigorous and systematic it does not hold science up as the model. It claims that all research is subjective in

that it is personal and cultural (Brewer 2000). Hamersley's account of subtle realism holds a belief in independent truth claims and that while no knowledge is certain they can be judged reasonably accurately in terms of their likely truth (Hammersley 1993).

While I had experience and training as a researcher in the area of health, it was grounded largely in the positive tradition. This would be my first experience of ethnography as a methodology and while certain methodological theoretical perspectives appealed to me e.g. 'subtle realism', my approach was pragmatic. My experience with positivism taught me than no research methodology was objective. However I felt that naturalism was better at transparency than positivism. It did not tend to claim what it could not deliver, e.g. objectivity and generalisations. I felt however that framing naturalism according to reactive positions to critiques from the dominant natural science further positioned science centrally. Methodologically I aimed to do what most ethnographers do when they practice field work: get close to the inside, tell it like it is, give an insider's account, be true to natural phenomena, and give thick description and deeply rich data. This methodological perspective abandons natural science models of research practice such as hypothesis testing, deductive analysis and description and measurement by means of assigning numbers (Brewer 2000). I did not totally abandon methods used in positivism taking a principled decision to use a mix of methods (see chapter 5) was based on an analysis of quantitative indicators to 'describe' health and deprivation in the study area. However the methodological position I chose was naturalism which is concerned with the study of social life in real naturally occurring settings; the experiencing, observing, describing understanding and analysing of features of social life (Brewer 2000). This kind of research starts with observation from which it endeavours to eventually build theory.

The principal methodological justification for ethnography comes from naturalism and the humanistic model of social research. An ethnographic approach involves a close association with, and often participation in social settings. It entails a combination of field techniques (note taking, audio, video recording, interviews, examination of indigenous literature, observations etc.) rooted in the ideal of participant observation (to live to some extent as the 'natives' do themselves). It is based on relations of trust and the belief that data are produced in and of interactions between researcher/s and researched (Fazlon 2009). Ethnography has

been mainly associated with qualitative research but can also employ a combination of qualitative and quantitative methods (Taylor 2002).

I established links with the department of anthropology, NUI Maynooth and attended a course in social exclusion as well as presentations from anthropologists using ethnography as their primary method. I regularly took advice from Senior Lecturer Jamie Saris (Department of Anthropology). According to Miles and Hubberman, core features of ethnography used in anthropology are that it,

- is based on contact with 'field' or life situations over a prolonged period
- encompasses a holistic view of the context under study which seeks to uncover its logic, its arrangements, its explicit and implicit rules
- attempts to capture perceptions of local actor "from the inside".
- explains how people in particular setting manage their day to day lives

There is little standardised instrumentation from the outset. Most analysis is done with words which can be assembled, sub-clustered broken into semiotic segments and organised to allow the researcher to contrast, compare, analyse and bestow patterns upon them (Miles and Huberman 1994a).

In line with Miles and Hubberman, the ethnographic approach I used stays close to the naturalist profile with extended contact in given social settings demonstrating a concern for the mundane as well as the unusual. As will be seen I participated directly and indirectly in local activities taking particular care to the description of local detail, people activities and perspectives.

Formulating the research question

As I pointed out the research question had been formulated before my involvement and reformulated after the initial field work and then refined through the course of the field work. The study's initial aim was to examine whether a community development approach could develop a role for community in Primary Care. Articulated as a question this becomes; can a community development approach develop community involvement in Primary Care? This is causal research.

My reading of the literature played a key role in refining and focusing the research question. Having explored the different meanings implied by *involvement* and its interchangeable use with *participation* I decided that I would employ what some authors describe as a 'meaningful' interpretation of involvement (Burnset al. 2004;Purdam and Crisp 2009) narrowing the scope of exploration to involvement in 'decision making about Primary Care service development or implementation'.

The initial conceptual framework presented in figure 5 arises from the original study aim. A conceptual framework explains either graphically or narratively the main things to be studied. Frameworks can be rudimentary or elaborate, theory driven or commonsensical, descriptive or causal (Miles and Huberman 1994b). The first conceptual framework was strongly influenced by PCs desire to show community development as an approach that could deliver the 'community participation' goal.

Designing a conceptual framework

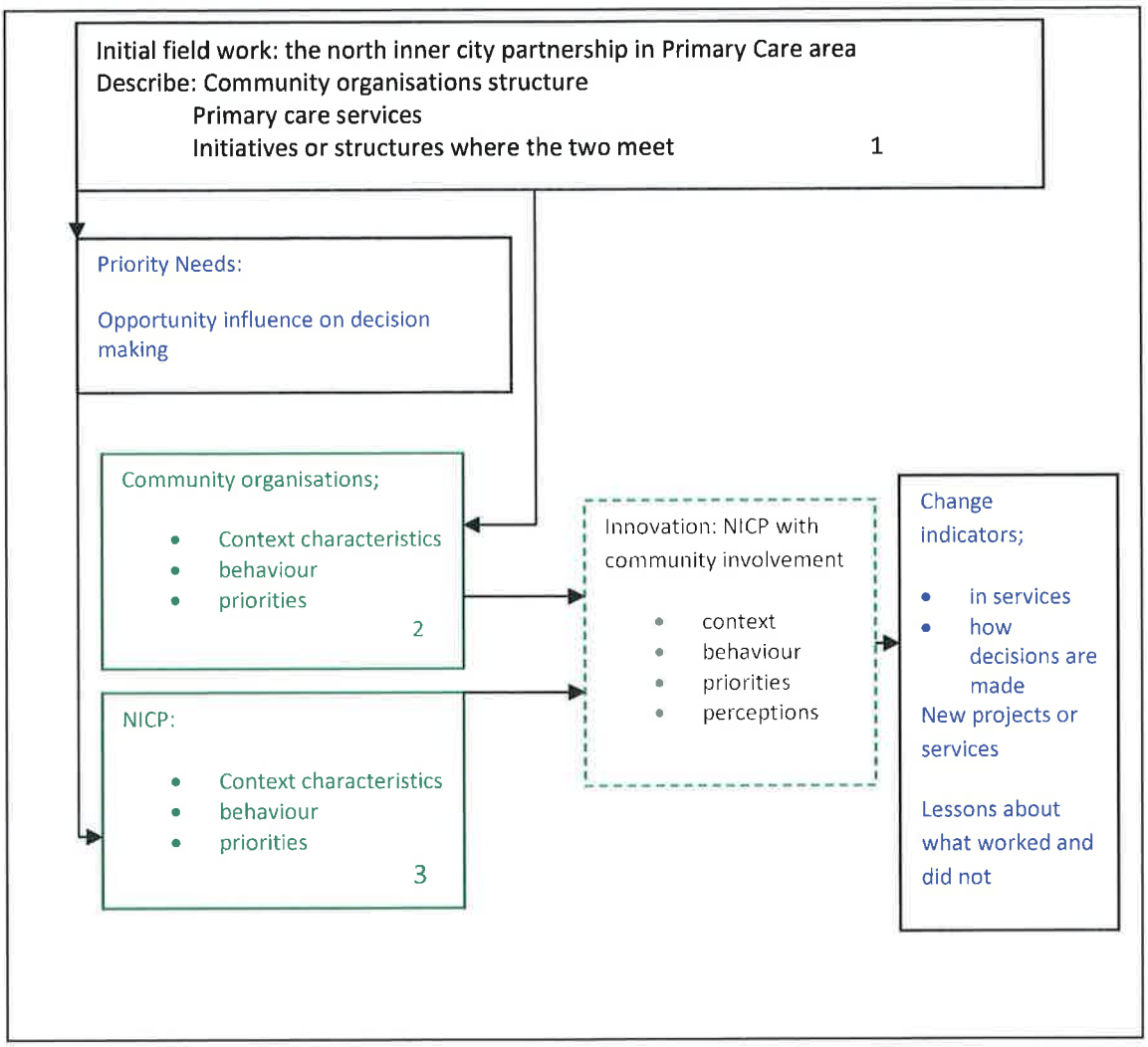
The conceptual framework in figure 5 is an example of what Miles and Hubberman call the 'bins' approach. Bins are intellectual containers of discrete events and behaviours (events, settings, processes, theoretical constructs). Bins come from theory, experience and the general objectives of the study (Miles and Huberman 1994b). This framework depicts the initial descriptive field work that would result in a description of community priorities and opportunities to impact decision making according to these. It displays the structures to be studied (community organisations: bin 2, North Inner City Partnership in Primary Care: bin 3) and within each the contexts, characteristics and behaviours. A very important 'bin' is depicted in this framework as virtual: bin 4. This is the 'space for participation' it was assumed would be created as part of the study. This site (forum / series of meetings etc.) would then be observed, studied as a discrete structure itself. Outcomes resulting from this new structure would be measured according to success indicators. The arrows indicate the idea that findings from sites will influence other sites.

The initial descriptive exploration of the field of study depicted in the framework did do as intended. It produced a description of the north inner city, the community group structure and activities, the Primary Care services on the ground, the places and spaces where community and Primary Care engaged and a description of activities and agendas of the North Inner City

Partnership in Primary Care. As anticipated too it identified from the community organisations' perspective, the priority needs of people living in the area. It also identified opportunities for influencing decision-making.

Findings emerging from this phase of field work challenged some of the theoretical assumptions made in the original plan, notable that community development as an approach had a long and strong history in the communities of interest, yet no need for involvement in Primary Care had been previously identified. My reading of theories of participation, space and power told me that the creators of spaces for participation generally had more influence over what shape participation took and who participated (Brock, Cornwall, and Gaventa 2001;Cornwall 2002;Gaventa 2006;Lukes 2005). Such theories further influenced my thinking on how this topic should be explored.

Figure 5 First[t] Conceptual framework: developing and evaluating community involvement in Primary Care in an urban setting



Green depicts spaces for exploration

Grey space to be created for exploration

Blue depicts findings

Conceiving of participation in spatial terms was helpful in highlighting the problems with the approach initially planned (Cornwall 2002). Theories of participation as spatial practice introduced in chapter 1 highlight the importance of examining how spaces are created to uncover power relations that can determine the very nature of participation (Cornwall 2004;Gaventa 2004). These were precisely the issues I was interested in exploring. The community development framework underpinning the first conceptual framework tried to relocate the lay community members within the prevailing order of things (as Cornwall

observes of some empowerment efforts), 'bringing them in, lending opportunities, empowering them, inviting them to participate'. As such a community development becomes a managed intervention rather than a process in which people discovered their own potentialities(Cornwall 2002). I did not feel comfortable managing such an intervention for two reasons i) there was a contradiction in using community development to meet our agenda rather than the 'communities'' ii) I wanted to explore power dynamics in the creation of participative spaces iii) I felt my role as researcher would be compromised by my role as community development worker. At this point I decided to redesign the conceptual framework in line with the naturalist tradition that would allow exploration guided by the developing frames of space and power rather than community development. I reformulated the question to a 'non causal policy' question; what does community involvement in Primary Care mean in a given context? (Smith 1987).

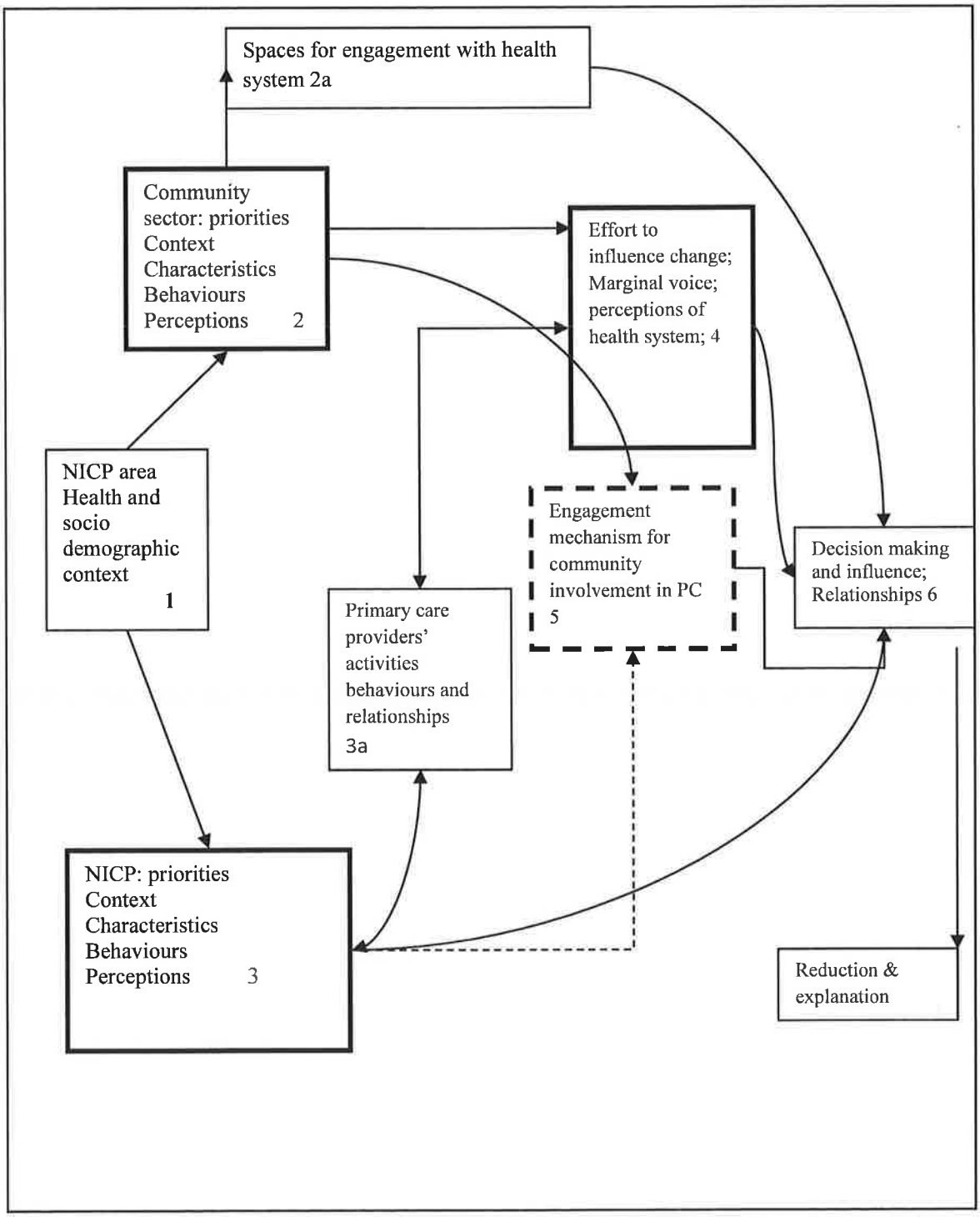
Phase 1 of the research was therefore governed by the first conceptual framework after which I developed a new framework to take account of findings. The first year of the project concluded with presentations of finding arising from the initial field work to both the community sector and the NICP. The Steering Committee led by PC who had championed the community development approach was thanked for the access and advice it provided and then disbanded. I continued to consult regularly with my supervisor DW and the NUIM department of anthropology for advice on ethnographic methods. The aim to develop the engagement mechanism between the community and Primary Care was not abandoned but was taken out of my remit and entrusted to a subgroup of the NICP management team. The role of prompting and supporting this was taken on by a GP on the management team AOC.

An emergent conceptual framework

Conceptual frameworks can also evolve and develop out of field work (Smith and Keith 1994). I developed a second conceptual framework that was influenced by the developing theoretical frame and the initial findings from the field. This framework (figure 6) allows for the investigation of an emerging 'participative space' which engages community members and primary care providers but does not depend on it. As the field work found some engagement between community and the health system (on a planning and decision making level) this was included for further exploration. As was the behaviours and relationships of the primary care

practitioners on the ground. Effectively this refocusing moved away from the institutional representations of community and Primary Care closer to people and practice. It also included a focus on a particular nested case study that evolved from the initial field work (bin 4). This developed as an action project in which I became involved in as an 'advocate ethnographer' (page109-110). It aimed to influence decision making based on the views and experiences of drug service users. Including such a case study allowed further interrogation of the power dimensions of participation. The arrows in the conceptual framework were drawn to show potential channels of influence discovered through the field work.

Figure 6 Emergent Conceptual framework



In the end the hoped for engagement mechanism between the NICP and community (bin 5) did not materialise. This meant that I did not have the luxury of situating myself in one particular site as originally envisioned. Instead I would have to move from site to site

investigating the same issues among different peoples and cultures that rarely intersected. Through the NICP in Primary Care I believe I had access to Primary Care decision making (though this turned out limited) and through the community groups' organisations network I had access community efforts to influence social change in the deprived inner city. I had to situate myself in different sites in order to study the phenomena which could not be accounted for in a single site.

A multi-sited approach

I took what is known as a multi-sited ethnographic approach (Fazlon 2009). This kind of ethnography purports to break with the convention that the idea of ethnography was to engage for a long period in *a* site of choice. Marcus (1995) argues that multi-sited ethnography defines as its objective the study of social phenomena that cannot be accounted for by focusing on a single site. Multi-sited ethnography has emerged for a number of reasons to do with ideas about space being socially produced and ethnographic space being no different; that societies are located within larger ones and focus on the seemingly bounded local was inadequate and thirdly for pragmatic reason to do with the difficulty for ethnographers to stay in one site for long periods of time. The size of a field work site conventionally has been described as one that could be easily traversed (on foot) in a day's work (Fazlon 2009). The North Inner City Partnership area was far too large to qualify as a traditional site (see map, appendix I). Falzon (2009) says if ethnographies are to take cities as their site, a spatial shift necessitates at least a reformulation of conventional methodology.

Had I situated myself in the formal structure of the NICP only I would have attended meetings and events followed agendas and priorities and visited NICP GP and health authority members' offices and surgeries on the ground. Through engaging with this structure and associated sites and people I would not have encountered the community group's structures nor investigated community agendas and problems. Through this lens I encountered representations of 'community' as patients of the Primary Care services only. There was no logical flow from this ethnographic site to the organised community groups and structures such as the Area Partnerships established through government in areas of disadvantage. To investigate community as an organised entity engaging with issues of concern to residents in the north inner city I had to engage in the distinctly separate ethnographic site that I describe as the community sector (chapter 7).

Deciding on which sites to engage with or 'making the cut' depends on access and the question at the core of the research. I had been given access to both the NICP in Primary care and the Inner City Organisatns Network. Beyond these I looked for case examples where there was at least an aim or desire (weak or strong) at some point, to support, or demand that, lay people from the locality or who use Primary Care services become involved in order to influence decision making. As required by multi-sited ethnography each site was fundamentally different.

> It appears that multisitedness actually means not just sites but spatialised cultural difference. it is not important how distant sites are, what matters is that they are different [otherwise] there would be absolutely no point in moving around. (Falzon 2009)

In summary then the changing conceptual framework and redesign of the research was influenced by my shift from the theory and the deductive approach I inherited on entry to the study to theories about space and power and an inductive approach. The community development theory and deductive approach made it impossible to examine power dynamics in the creation of participative spaces which I felt were fundamental to understanding community involvement in Primary Care. The redeveloped conceptual framework was influenced by a new set of theories (outlined in chapter 1) and allowed for exploration of such issues. The conceptual frameworks prompted the specification of bins that hold discrete phenomena and divide conceptually discrete variables making suitable questions and methods more apparent for examining different 'bins' or relationships (see table5) (Miles and Huberman 1994a).

Sampling: A funnelling approach

Good qualitative research is more of a circular process than a linear one and analysis is part of a larger interpretative process which begins in the formulation of the problem and method of investigation (Crabtree and Miller 1999). As I had access to two very different worlds in the same geographic area, I entered these worlds separately and in parallel, ultimately wondering why they were separate. The NICP was the starting point for the study and was coherent as an ethnographic site it contained meetings, peoples and following theses along, GP practices in a large chunk of the city. The community groups network (ICON) in the same part of the city was

more diverse and less coherent as a site. It comprised meetings and projects in a large chunk of the city within the NICP area. As the breath of things and people to observe was too wide for me as a sole researcher I began by using what is described as a funnelling approach to sampling (Miles and Huberman 1994b).

I moved back and forth between collecting, reflecting analysing and writing. Analysis led to further questions which identified further people to talk to, sites to visit and events to participate in. Theory too contributed to selection of cases for further exploration.

Firstly I used mapping to get a sense of the geographic area and the structures within it which were important to my study topic. I drove around the area cycled, conducted 'transect walks' talked to people I met and took pictures. The difference between very affluent and very poor areas was striking. Mapping of the physical health infrastructure had been done by the NICP Partnership and of the community organisations by the Dublin Inner City Partnership and the community networks. I used these as templates from which to select sites for further focused observation through site visits. I contacted community organisation to find out more about what they did and whether they had any involvement in health issues. At the same time I utilised secondary source quantitative health and socio economic data to develop a categorising indicator of health and deprivation (see chapter 5).

In the initial fieldwork I moved around a lot, going in and out of different sites in the geographic area covered by the NICP in Primary Care that were relevant to Primary Care and Community sector: health centres, community forums and projects, community projects, GP surgeries, health authority administrative offices, council offices, homeless hostels. I visited these places interviewing or talking to people who could tell me about what the community sector or the health sector was doing. My aim was to gain a grounded understanding of the health system and activities carried out by the community sector (groups and organisations). I wanted to see how they related to each other in the area.

As Latimer puts it, 'a research project 'thinks' the field up in ways that have distinct political effects' (Latimer 2003). My analysis of the whole geographic site covered by the NICP in Primary Care found a large and heterogeneous area in terms of health and deprivation. Drawing on the social determinants of health theory I focused more narrowly on areas of

deprivation. Such theory introduced in (page 36-37) shows how ones environment and living circumstances, community networks and control over ones resources have a more significant influence on health outcomes in poor areas. Unsurprisingly there was more community group activity in areas of deprivation. These factors concentrated the presence of the elements I was interested in. Theoretically then community influence on health planning and development would have greater significance if these areas. Theories of power encouraged me bring into the frame those who were not involved in the decision making spaces as well as who were. This led me to explore decision making arenas that the community sector prioritised and ask whether Primary Care was involved.

I realised that if no participative space was developed by the NICP (bin 5, figure 6) it would be difficult to identify prospectively barriers to forwarding of community voice on health matters. It was at this point that I decided to follow two case studies that would help to illuminate barriers to involvement. The first case was an effort to influence health service for drug users the second was the development of a new Primary Care service. In the first I wanted to see would the services and decision makers take heed of drug users' views, in the second I wanted to see whose views would influence decision making. In essence I as looking at two sides of an equation with different missing variables. I took opportunities that arose naturally. In the first case I became involved in an initiative called the Participation and Practice of Rights Project. I became active in forwarding the voices of the drug service users to influence the health system that served them. This changed my role from purely participant observer (page 109). In the second I observed the development of a new service (GP 'Out of Hours'), from the side-lines (access to a closer observation was impossible). I interviewed key informants and followed media releases.

Methods

As can be seen from the table 4 below while relying most heavily on qualitative methods I used quantitative methods to describe, categorise and map the health and deprivation of the population living in Dublin's north inner city. The construction of the indicators are further described in chapter 5. Qualitative methods included participant observation, interviews, focus groups, mapping questionnaires and document review.

Table 4: Questions and Methods

	Fieldwork Site	Questions	Methods used
1	Study area (geographic area)	What are the characteristics of this space? How are people grouped and described? What engagement processes exist?	Creation of quantitative index using Secondary source statistics health and CSO data Mapping of indicators to Ordinance survey maps Transect walks Descriptions
2	Community sector (community groups and networks)	How is this sector organised? What activities go on here? How are priorities determined? What do people in this sector thing and do south health issues and services? How is community voice assessed and represented? How is influence exerted?	Interviews? Mapping questionnaires Participant observation Document review
3	NICP Partnership in Primary Care	Who is in this space and what views are represented? How are decisions made? How did it develop? What are the relationships? Who is in control?	Interviews Participant observation
2a	Spaces where community engaged with health system	Why was there engagement? Who was involved? Did community voice influence change?	Interviews Participant observation
4	Case study :marginalised voice	What do drug users think of the health services? What would they like to change or develop? Will the service providers take account of their views? How will the group work together?	Focus groups Participant observation Outcome matrices interviews
4a	Case study: development of a primary care service	Who is involved? How are decisions made? Who has most influence? How is power used?	Interview with key informants Collection and review of press releases and media statement

Descriptive observations start when the researcher enters the social situation initially to get an overview and determine what is going on. I started with broad *grand tour* questions were asked: How is space organized? What is going on? Who are the actors? What are the activities? What objects are present how are they used? In each of the sites (numbered in the conceptual framework) I asked initial questions that grew in number and became more

focused as the data grew. I used a number of sources and methods to answer questions emerging.

Interviewing: All interviews regardless of type use questions to illicit a responses whether recorded in written or tape form. They collect verbal report of behaviour meanings attitudes and feelings. This is based on two assumptions: the respondents verbal responses are a good indicator of these, and that the researchers questions are a good indicator of the subject of the research. The later of these was of most concern to me as Brewer points out

> 'ambiguous concepts and theoretical ideas can also be difficult to operationalize in questions simple enough for people to understand while still reflecting what research intends'

One good example of this and indeed a significant finding in itself was that people living in the study area and working in the community groups were not familiar with the term 'Primary Care'. Conversely, GPs were not familiar with the concept of 'community involvement'. I had to avoid these terms and so I started with simple interview schedules for the different groups and conducted semi-structured interviews. With key informants who I met with regularly and with whom I built up a relationship, I conducted unstructured interviews that literally recorded what Burgess (Burgess 1984) describes as 'conversations with a purpose'. The aim is to avoid structure so that 'exploration of respondents meaning is untrammelled by formality' (Brewer 2000)

In the initial mapping phase of the field work I conducted 34 semi-structured interviews. Throughout the focused field work largely conducted in the 3 domains identified in the 2nd conceptual framework I conducted scores of informal and formal interviews (face to face interactions). I conducted 28 in depth interviews which I recorded on tape and transcribed. I also collected and studied management meeting minutes and progress reports. I kept notes and held informal interviews about developments surrounding the spaces I observed (e.g. the development of the 'out of hours' service).

Focus groups: The purpose of a focus group is to listen and gather information. It is a way to better understanding how people feel or think about an issue product or service. Participants are selected because they have certain characteristics in common that relate to the topic of

interest (Krueger and Casey 2000). I used this technique along with participant observation to explore drug users' behaviour, meaning, attitudes and feeling in relation to health issues and services. I developed a question route (see appendix II) for the moderator (ER) to use while I observed and took notes. ER was a peer of the focus group members who also worked for the drug users forum (UISCE[2]). In her role she was used to collecting drug service users' views and was seen by them as an empathetic ally who they could trust. She also became a key informant for me throughout the research.

The three focus group sessions with a total of 26 participants were tape recorded providing six hours of taped conversation. Transcription was not straight forward. It was difficult to hear what people were saying for a number of reasons i) low flat tone and accent ii) hot summer's day required that windows be left open allowing city noise iii) in spite of ER's efforts to get people to talk one at a time there were times when everyone spoke together.

Also my question route had assumed a clear sober logical thinking pathway. This was not the case. Participants were all opiate users and some were clearly under the influence of legal or illegal chemicals. Participants sometimes did not understand what was being asked or wanted to talk about something else or found it difficult to express their point. The following extract illustrates this:

ER So J can you list the services that you have attended over the last two years?

(phone rings loudly in the next room)

Participant J Sorry say that again

E R Could you list the services that you have attended over the last 2 years, in relation to your health? Your health, OK?

Participant J Tryin' like, is it?

ER Pardon?

Participant J Goin' different places is it?

[2] The Union for Improved Services Communication and Education (UISCE) is a drug users forum based in the North Inner City.

E R Yeah, any place

Others chime in: Hospitals.. your GP

Participant J There's only one place at the moment can't think of the name of it. I can't even think of the name of it. It's up in Richmond road somewhere, does anyone know the place it's near where Brendan's.. (St Brendan's Hospital is a Psychiatric hospital)

Other's talk at once.

Participant J No not Vincents' (another Psychiatric Hospital)

Participant P Is it kinda a Psychiatric place?

Particioant J Yeah, it's a detox. for or drink

(phone ringing again)

Participant J I can't think of the name of it. They wouldn't take me in there, 'cause I'm on methadone.

ER Is it a Psychiatric hospital?

Participant J No no

Others talk together trying to come up with the name of the place

Participant J I wanted come off the drink but they wouldn't do it cause I was on methadone. Can't think of the name of the place, but I will get the name for ye

Participant F: Stanhope Street is it?

Participant J That's it Stanhope Street yeah

Participant F: Stanhope Centre

Participant J Nice one buddy

Participant CF: Are you on a clinic?

Participant J Yeah, I'm on city clinic but they won't do fuck all for me over there

The exchange goes on with ER endeavouring to establish which health services J uses. This whole exchange takes 4 minutes and having started out saying the only service he has attended in the past two years for his health was the Stanhope Alcohol Treatment Centre, ER

establishes that in fact he also attends City Clinic Drug Treatment Centre, he has a medical card and a GP.

In the course of this exchange, ER tries to understand what J is trying to say as well as getting him to answer the question. J tries to describe how services are not giving him what he needs, that is in his view, help to give up alcohol. Others contribute trying to help J to communicate. The exchange is further complicated by another interruption; a participant who comes in late does not look well and appears drowsy. Others are concerned about her and talk about how she looks and offer her a cup of tea. They mention she is "only outa hospital". CF (acting as ER's assistant) goes to make a cup of tea for her.

While answering the question: what health services have you attended? J provides much more information than he is asked for. He describes himself as alcoholic. He reveals that he does not believe he has a drug problem saying he is "only on methadone and doesn't touch anything else". He is clearly unhappy with the drug treatment clinic services and believes "they don't care" about him. He describes how they discourage detox from methadone (he does not want to see a counsellor which is a precondition for detox). He has no confidence in the drug clinic helping him with his drink problem. He is also unhappy with his GP as he says she will not give him anything because he is "on the clinic". Being 'on' a clinic is used instead of 'in' a clinic as a synonym to being 'on' methadone which is considered by many as more addictive than heroin. Being 'on' a clinic implies certain rule and regulations and daily attendance so that one's life is controlled in similar ways as being 'on' drugs. Therefore use of 'on' rather than 'in' is therefore a more accurate reflection of meaning from the drug users' perspective.

The question route was hardly used in the end and only served as a reminder for ER of issues to discuss with the group. While there are obvious difficulties with this approach I discovered that it was often in, *not* answering the question (as above) the most useful information was provided.

Participant observation (PO): Social research involves observation of people in their natural social environment. It is the data collection technique most closely associated with ethnography from its origins in classical British anthropology. It involves participation in the daily life of informants in their natural setting: watching, observing and talking to them in

order to discover their interpretations, social meanings and activities (Brewer 2000). The main instrument in participant observation is the researcher. This necessitates a proper balance in the observer's dual role of part insider and part outsider allowing them to get close while maintaining a professional distance and critically reflecting on data gathered (Burgess 1984).

Wolcott classifies participant observation according to the level of participation within a setting: active participant, privileged observer and limited observer (Wolcott 1988). Hamersley (1983) describes most field work as occurring between the two poles of complete observer or complete participant. The complete participant gets access to the inside information and experiences the world in ways close to other participants. However biases of over rapport may influence findings. The complete observer generally avoids the risk of 'going native' but may be at the risk of failing to understand the perspective of participants.

Researcher Role and Reflexivity

In this study participant observation is what Brewer (2000:61) describes as pure i.e. the acquisition of a new role to research in an unfamiliar setting. Though I had trained as a nurse in Dublin many years previously, I had been hospital based. Services based in the community were unfamiliar to me. While I grew up in Dublin I had only a cursory knowledge of the study area and no knowledge of the community groups and sector operating there.

In different sites I adopted different roles. In the NICP I initially felt my role was closer to observer than participant. I had no other role other than observer (and occasionally tea maker). Participant observation took place at meetings, AGMs and in health authority offices. In the community sites my role was at times closer to the centre of the participant observer continuum. I made available my analysis of the health and deprivation to ICON and presented this when I was asked. I served as a steering committee member on the Participation and Practice of Rights Initiative and latterly towards the end of my field work when the Health Action Forum (HAF) was established I served as part of this committee. I played the role of facilitator in the case study to influence drug services using an advocate ethnographic approach (Fetterman 1998). An advocate ethnographer allows participants to define their reality consider their view about the ideal solution and takes and active role in making social

change happen. With the other collaborators[3], I published the findings of the focus group discussions (O'Reilly, Reaper, and Redmond 2005). This publication presented the voice and of the drug users on health services. In this report drug users as treated as the authority. Their voice and words describe things as they are. These voices are there for treated differently than those in other sites in which I engaged. They present the facts rather than illustrate someone else's narrative description. This strategy was a conscious one that aimed to give ownership and power to those who experience the services as service users.

I did not simply decide on the roles I assumed and stick to them but rather found I was influenced within the different sites to adopt these roles. I had fully intended to be the 'privileged observer' with no other role in all sites. This did not happen and I found I behaved in a way that I felt made me acceptable to the group I was observing. Savage's ideas about adopting bodily practices (she calls participative observation) as a way of gaining access to others worlds goes some way to explaining my emergent roles in each space (Savage 2003). She suggests that knowledge can be gained from others by adopting their bodily practices or dispositions. While I did not set out to do this, on reflection I believe my desire to gain access to how groups act and think and act, influenced certain of my bodily practices (including dress). This has a bearing on role as participant observer. For example in NICP meetings with health authority managers and GPs I found I could sit writing notes just as the secretary did. By copying other health authority staff I learnt not to show facial expressions of interest, surprise or shock and never to give personal views, opinions or offer ideas or solutions, regardless what was being discussed. The reverse was true in spaces where community groups and members convened, here I would be expected to show for example indignation at what the government or authorities were doing now. I was expected to contribute views and opinions and information. With the drug users, sharing cigarettes and outpourings of empathy was important as was physically hungering down or sitting on steps outside clinics or in congregations. In each site, imitations of bodily practices helped me fit in but also, on reflection told me something about the social structure I was fitting into. In each site too demonstrations that we are the same were important but most important among those who felt different (see reflections page 289). My role was therefore influenced by the very norms I

[3] Participation and Practice of Rights Project, UISCE (drug users forum) & the Mountjoy St Family Practice.

aimed to explore. In the NICP it was acceptable to have no other role other than note taking, to say nothing and contribute nothing. In the community this was not allowed everyone had to have a purpose and contribute. Among the drug users being on the same level (sometimes physically sitting on steps outside clinics) not judging was more important than roles or purpose.

Reflexivity allows the researcher's experience of doing the study to be included in the analysis and therefore can highlight areas of greater and lesser subjective connection between researcher and consultant (Ellis and Bouchner 2003). I tried to account for myself and social relations in the text as well as my broader values commitments and preconceptions rejecting the notion of what Brewer describes as,

> the detatched , aloof and objective researcher who produces knowledge claims as if in a vacuum, in favour of one who not only engages with their subjects but also reflects upon the processes by which conclusions were reached.

Reflexivity and the writing process have been described as inseparable and reflexivity and interpretation as integrally bound together (Brewer 2000). Therefore through the ethnographers' reflections on the social processes that impinge upon the data as well as the nature of the social interaction between the researcher and the researched that influences how the data are interpreted and conveyed, much of the analysis and interpretations done! Yet much of interpretation is acknowledged as a creative process depending on the insights and imagination of the ethnographer about which little can be written. Hard as we try to make this interpretation explicit, still much goes on in the sub conscious level through our bodies (as Savage discusses) and our emotions. If this were not so the 'thunderbolt' flash of clarity would not be a surprise but an expected incremental dawning. Nevertheless we are required to make explicit those portions of the analysis that we can describe.

Reflection on my different roles within different sites helped me limit bias. I felt I was most in danger of 'over rapport' in the case study on marginal voice and most at risk of not gaining access to health authorities' perspective. This reflection, which I noted in reflective notes' therefor, influenced analysis and further exploration. I ensured that analysis of the case study on marginal voice was even more rigorous and multi-layered constantly gaining multiple views of outcomes. This included follow-up of and feedback from meetings and actions using

matrices that were then validated by stakeholders. The purpose was to ensure the closeness I had achieved and my advocate stance would not overly bias my findings.

I went further to gain health authority's staff perspective. I met for coffees and semi social occasions and included more in-depth interviews. I also discovered that arriving early and helping set up for meetings was a unifier.

Data management and processing

I kept a long chronologically ordered document of all my field contacts. It contained references to filenames and paths where all associated material either hard or soft copy, photos, maps and data displays were stored. I created word document for each of the sites in to which I added processed field notes from each site. I delineated interpretive or commenting memos in different colours. Eventually as this became unwieldy I further subdivided my master document in to four creating one for each site and one for the two case studies. Each cross referred to associated documents and interviews. Other data types evolved from these masters to separate files e.g. – more fully processed write-ups, coded data, memos of reflection on conceptual meaning of the data, power point presentations and analyses of segments of data. For easy retrieval these were referenced and described in the original document. I recorded, transcribed and filed my formal interviews and focus group discussions and referenced them accordingly.

Notes from the Field

I used notebooks and Dictaphone to record field notes either during or directly after a contact or period of participant observation. My questions for particular sites (originating in the conceptual or theoretical framework) served as a standard template for field notes so that I aimed, as recommend to describe physical space, actors, activities, objects, events, acts, group goals, feelings (expressed or observed) (Streubert Speziale and Carpenter 2003). I recorded my own thoughts, feelings and reflections by bracketing them or for more lengthy reflections, appended them to the particular field notes clearly distinguishing them as *reflective*. I then wrote up these notes more fully once out of the field.

Excerpt from focused observation notes (21.03.05), GP surgery:

The exert below is taken from field notes which I processed from notebook to file after a period of shadowing a GP. The notes were jotted down while sitting in the corner of the consultation room and written up more fully after the period of observation was over.

> A woman enters the consultation room. She is coming to have her daughter tested for asthma. An inhaler is necessary for this test but because the doctor was absent on Friday, the inhaler has not been ordered. He asks the woman if she will go down the road to the pharmacy to collect the inhaler. He gives her a prescription for it and, I think, rings the pharmacy to let them know she is coming. He apologises and starts to examine her daughter. The daughter has a cough. The doctor lifts the girl onto her mother's lap and takes her coat off. The mother says "She's coughing".
>
> "Yes, it's doing the rounds," agrees the GP.
>
> "Now Hannah hon," he talks to the child and asks her, her teacher's name. He listens with a stethoscope to her front and back. The doctor coughs himself. He checks her throat, her ears and says she has a cold and writes a prescription for a cough bottle. The mother says her son has it as well. Yes, he'll give him a prescription too. He explains that one in ten with these symptoms get worse requiring an antibiotic. He says,
>
> "I had it myself last week." The GP tells her he will see her immediately once she collects the inhaler. He starts to draw a map of where the pharmacy is, but there's no need, she knows.

Excerpt from reflective notes (25.6.2004)

By keeping a record of my thoughts and feelings and how I was interpreting what I was observing helped me to make these explicit and therefore be part of the on-going analysis. In an excerpt from notes I had written after one of the NICP general meetings I acknowledge preconceptions I carried about doctors from previous experiences:

> *I have come into this with my own preconceptions largely about the medical profession. I have after all been a nurse in the hospital hierarchy that saw doctors as superior to nurses. At the meeting I observed group behaviour which I think is GPs doing what I expected doctors to do 'call the shots'. The fact that we (the Health Board staff and me) were excluded from the room while the GPs had their own private meeting first is reflective of the 'us and them dynamic' in existence.*

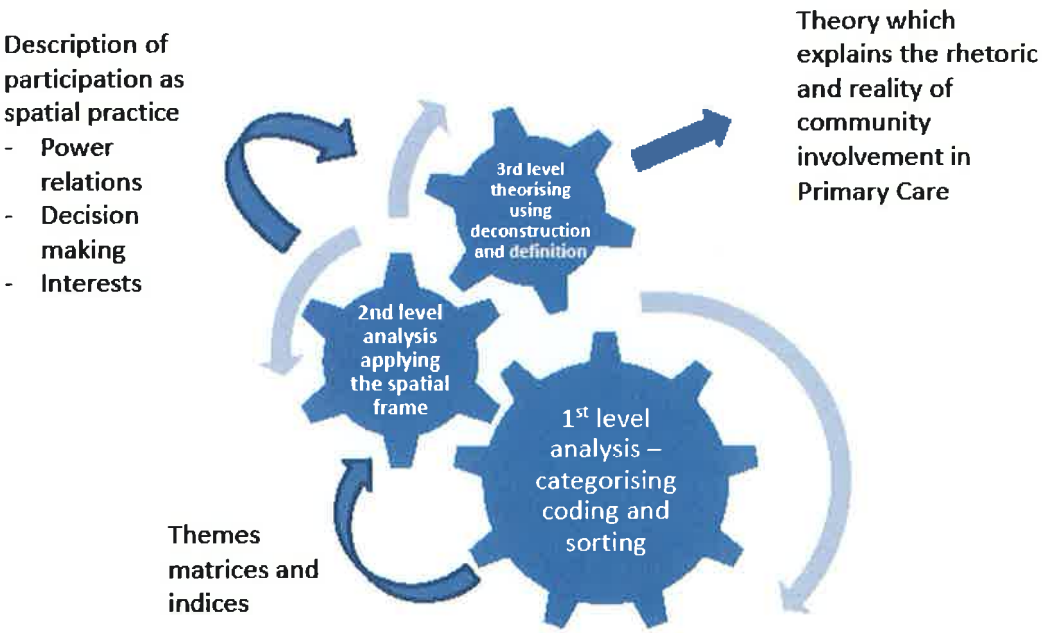
My feelings of exclusion encouraged me to empathise with others also excluded (health authority staff) reflected in my language 'we'. Writing about how I felt, as well making my

preconceived assumptions explicit helped me both challenge my interpretations and understand the perspective of those I was sharing experiences with and encourage me to break boundaries to see what was on the other side of the 'us' 'them' divide.

Analysis

Analysis was a continuous and iterative process that commenced during the design of the project and continued through the data collection and interpretation of findings. Analysis influenced sampling (above), which was grounded in data from the field. As such analysis was a circular spiralling process making it difficult to display in linear stepwise manner that is the default of writing. Writing itself was part of the analysis clarifying and organising thought (Hammersley and Atkinson 1983). There were however levels of analysis discernible which are illustrated in the figure 7 below. Outputs from each influenced on-going data collection, focus and further analysis and interpretation.

Figure 7. Analysis: a spiralling circular interpretive enterprise with varying levels



Level one analysis

Coding is different at different levels of analysis ranging from descriptive to inferential. Pattern codes pull a lot of information together making connections between data denoting single themes (Miles and Huberman 1994). I applied descriptive codes in margins while reading my field notes and interviews both to get a sense of the type of codes emerging and also to summarise and highlight what the data contained making retrieval easier (see example of initial coding below). Initial codes are descriptive summing up a few lines or paragraph with a word or two describing what is happing. These are first level codes are for summarizing segments (Miles and Huberman 1994).

Excerpt from field notes with 'initial' summarizing codes

I arrive at the meeting venue in what used to be part of the old psychiatric hospital buildings. Something caught my eye to the right about 50 yards further up on the path (outside the medical card section CCA6). It's a body. I take note and continue on to where the meeting is to be held catching up with 03, 05 and 04. I tell her that I'll be back in a minute I was just going to check on the body.	Old asylum now admin offices Pass body on way to meeting
I run back out and on the way collect the porter going to investigate the man lying fully across the path. He's 30ish. I approach him (he's asleep or unconscious). I did wonder if he might swipe out if I disturb him. He doesn't. I discover he's homeless and waiting for the psychiatric hospital assessment unit to open "I'm hoping they'll take me in" he explained. "The divil drink" the porter explains and offers to go over and notify the assessment unit of this prospective patient.	Homeless man wants admission Porter diagnoses & notifies service
I rush back to the HQ of Community Care Area 6 leaving the man lying on the path while the porter saunters across the road to the security in Brendan's Psychiatric institution.	Rush to meeting
02 (03s assistant) makes the tea – I go to help. Paper cups teabags... "Nice sandwiches" everyone agrees... "Bought in" we're told.	Stroll to deal with man
Chat is about the sandwiches... how nice they were... the kitchen in the adjacent building was now closed because of mice infestation.	Conversation- Tea & sandwiches (safe)
I give a brief report on the body no one is interested. It transpires that 04 and 03 had seen him.	Disinterest
(Odd juxtaposition I think – body outside old asylum, looking for asylum as HA inside having tea and sandwiches. 40 yrs ago prior to plans to empty the psychiatric institutions he'd be inside having tea and sandwiches	(Staff inside Patients out)

Further reflective notes show how I felt 'odd' or different from others in the meeting who I had come to know. I was rushing around *as if* there was an emergency while they were calm and ordered getting the sandwiches and agenda ready. These reflections about differences

between my actions and the others at the meeting served to highlight certain group behaviours and activities that helped give an impression of calm.

After initial coding I then made a template of codes that took account of what I wanted to find out from the conceptual and theoretical framework and specific initial codes in which I was interested (e.g. the 'tea conversation' became important). I also applied free codes (in NVivo) as they emerged through reading and re reading the data. Codes, sometimes referred to as open codes reflect meaning rather than description (Emerson, Fretz, and Shaw 1995). An example of a this kind of code is 'labelling' that I applied to descriptions of a category of things drug users said they didn't like about hospitals such as:

> *'The way they have that luminous thing so that doctors know and nurses know that your drug related once they see that sticker".*

To select themes (or pattern codes) I first looked at my 'initial' codes to see if they naturally grouped under some category or description. I also gave consideration to those which spoke directly to central research questions e.g. in analysing field notes from shadowing Primary Care Practitioners the theme 'fragmentation' arose from grouping codes including 'separate services', 'no communication', 'going different places', 'isolation', 'not aware of services'. I then added this to the template of aprioi codes for further analysing data from different sites and at different levels. Themes or pattern coding helped to reduce large amounts of data into smaller analytical units.

Having read and re-read and coded data relating to the same subject category I wrote interpretive memos commenting on what I believed was going on in the data in terms of insights and ideas. The following is an example of a memo I wrote after coding notes and interviews relating to my initial field work shadowing Primary Care providers and conducting site visits and interviews with community groups:

PHNs were embedded in the community and their work merged with community at times. They negotiated through non definition of role, a path between the medical and social models of health making them a necessary part of both. Other practical players in the health service for example the CWO provide the health service with the ability to impact social determinants in extremely vulnerable groups. However lack of understanding or agreement about their role as part of health and the lack of debate on what this is means that are underutilised by Primary Care services and providers.

Interpretive memo

Level two analyses

Data reduction: This involved selecting units of data from the universe of data. I organised my data according to the different sites in which I engaged. For each site I included selected data which itself was already analysed using a specific approach (e.g. focus groups according to emerging themes and follow up according to matrices describing reactions and influence). I wrote and rewrote these texts edited and reduced numerous times. Wolcott (Wolcott 1990) suggests that writing is not separate from analysis in that writing clarifies thinking and thus clarifies both.

In the NICP for example, I selected data relevant to decision making mechanisms in Primary Care and asked questions about the nature of power relations. I included observational data from management committee meetings and general meetings, interviews with partnership members, all minutes of meetings during the time of my engagement and for two years previous and all annual reports. As a result of findings showing that decisions in this space were dependent on decision making in other spaces I followed this thread to include data from interviews with key informants and media from those related spaces.

In the sites I explored to understand community health activity and priorities I included data that provided an understanding of community groups and residents' priorities and views and how they related to health. Data largely included interviews with community workers and community members, observations at key conferences and community events as well and meetings of a health action forum which began to emerge in part as a consequence of this study.

Unlike the two spaces above, the third space was co-produced as an ethnographic space through this project in collaboration with others. The data selected can be broken into two categories i) that produced through the formal focus groups and ii) that relevant to the efforts to influence services on the basis of focus group findings. Data included focus group data, observations and follow up meeting of the collaborative group and meetings with service providers. The guiding principle for data selection for this site was the views and voice of the drug user. This unconsciously (at the time) tends towards humanistic ethnography which attempts to 'tell it as it is' on members own terms (Brewer 2000:107).

Applying the interpretive frame

Interpretation is a creative enterprise that depends on insight and imagination, it occurs simultaneously with the post indexing stages of the analytical process (Brewer 2000). Organising and describing data according to Cornwall and colleagues' typology of spaces for participation as well as theories of power facilitated further synthesis and interpretation (Bachrach and Baratz 1970;Cornwall 2002;Cornwall 2004;Foucault 2000;Gaventa 2002;Gaventa 2004;Lukes 2005).

I used the theories of participative spaces with theories of power introduced in chapter 1 to categorise and further interrogate the data. I used the one, two and three dimensional views of power to uncover how power was used in relation to decision and non-decision making in the community sector and the NICP in Primary Care. This helped to highlight power relations in real and potential spaces for participation. The drug users were not involved in decision-making or with others to apply the power in decision making frame. I used Cornwall's typology of participative spaces to analyse and categorise my findings in the various sites and cases.

Data display: Quantitative data in chapter 4 is displayed in map form to give a sense of the spatial nature of inequalities. The following four chapters represent the sites of my participant observation; Primary Care services; community groups; drug service users and providers and the NICP. There are written and presented to convey a sense of movement, a story unfolding as a way of reflecting everyday life over a period of time. They are an attempt to give a reasonable representation of reality in each space. However as Hammersley (1993a: 25) contends they are not infallible and are a selective representation.

I used key events as a lens through which to view behaviours. I contextualised my descriptions historically taking account of significant Primary Care developments. I triangulated findings with data collected from interviews and observation and documentation collected from the various sites. After each field visit I read and typed field notes and identified questions or gaps to follow up on next field visits. I reviewed the data in manageable units to conduct analysis.

Theory building

Theoretical statements differ from descriptive statements in that they are abstract propositions. I attempted explanatory theory of the mid-level range which is more limited (Brewer 2000). The blend of theories I used on space and power helped explain findings in the three sites however they did not provide an overall explanation at the theoretical level for the disconnect between Primary Care and community I had found. I was drawn to Derrida's notion off deconstruction to identify the 'aporia' or logical dilemma beneath most texts making them deconstructable (Collins and Mayblin 2005;Rolfe 2005;Wolfreys 2007). Using the idea of the 'aporia' I locate the logical dilemma present in notions of community Involvement in Primary Care. Using this with ideas about how disease and approaches to care are framed helped explain why things are the way they are(Aronowitz 2008).

Validity: A number of processes were used to cross check emerging findings, with other sources as well as other data types. Triangulation is an attempt to get a true fix on a situation by combining different ways of looking at it or different findings (Silverman 2000). The ethnographic approach also requires a constant iterative process. This included going back to the same interviewees to check interpretations, presenting emerging findings to the groups they related to, and discussing the emerging findings with key informants to see if they 'rang true'.

Ethical considerations

I received ethical approval from RCSI's research ethics committee. Interview consent forms were signed by participants, once a complete explanation about the research purpose and process was given. I made principled decisions about which data to include and leave out in order to save any participant from potential embarrassment or unwanted identification.

Limitations

The limitations of this kind of research have consequences for generalizability, reliability, and objectivity (Brewer 2000). However I have tried to counter these weaknesses through a rigorous and systematic approach and by providing rich data. I consistently tested my interpretations with participants and against data from other sources. Through theorising this data further in the final chapter I attempt to combat the criticism of lack of generalizability so

that what I conclude can relate to notions of Primary Care and involvement in many scenarios. In the end the findings of this research are my interpretations having spent years looking at these issues in practice and in theory in different parts of the health system and community settings in Dublin. I aim to present them as authoritative and widely relevant rather than objective and generalizable.

The decision to conduct multi-sited work invariably has a cost on depth. Multisited ethnography allows a research topic be explored through multiple spaces which can be geographic social or virtual. This can be potentially limiting because it does not proide a clear direction for the research to follow. I believe the redesign of the conceptual framework and the development of my theoretical framework helped clarify direction and selection from otherwise multiple options. The trade-off between depth and the mutisited approach I believe was necessary as one site would not have provided an adequate variety of data to understand the research topic.

Timeline: The following table presents the study timeline

Table 5: Study timeline

	2004 2nd Q	2004 3rd Q	2004 4th Q	2005 1st Q	2005 2nd Q	2005 3rd Q	2005 4th Q	2006 1st Q	2006 2nd Q	2006 3rd Q	2006 4th Q	2007 1st Q	Break	August 2011
A														
B														
C														
D														
E														
F														

A Initial exploration & mapping of study area health and community infrastructure

B Community groups and action C Marginalised voice: forwarding the drug users agenda

D North Inner City Partnership in Primary Care E Read, describe, analyse

F Formal write-up

Chapter 4 The Irish policy context

This section examines the policy arena in which Irish Primary Care and community involvement are situated. Here I trace and describe policy development prior to and during my field work. The practical implications of these policies require the bringing together of two cultures to make up Primary Care Teams. I introduce what this means in practice and provide some background to the development of the two cultures in the first place. Relevant policies are analysed and presented at appendix VII.

Policies on community involvement

Before the national strategy for Primary Care was defined policy documents recognised the need for community participation. However it was not always clear what this meant and tended to be more towards, the 'consultation' rather than the 'control' end of the spectrum. An analysis of health policy documents in 2005 found that commitments to the value and importance of 'empowerment' and 'capacity building' were not often seen (Combat Poverty Agency 2005c;Department of Health and Children 2005). The analysis concludes however that 'most current health policies can be seen to have adopted a social model of health, at least in principle' (Community Workers Co-operative (CWC 2005).

While explicit national policy development on community involvement was underdeveloped prior to the 2001 national strategies implicit policies governing community care services in the Health Board system demonstrated aspects of the social model of care with services including community welfare officers, community development workers as well as the more traditional health care workers (Eastern Health Board 1980a;Eastern Health Board 1980b). Services served catchment areas and financed significant numbers of community and voluntary groups under 'section 65' funding to provide services. For example in 2000 the Northern Area Health Board funded hundreds of voluntary sector organisations to the sum of over 20 million euros in grant funding representing approximately 10% of expenditure (Northern Area Health Board 2001). Also Health Board statements referred to the Alma Ata model of Primary Health Care which sees community participation as an integral part (Department of Health (DOH) 1995;Eastern Health Board 1995;Eastern Health Board 1999;Watson Wyatt Worldwide 2003;Western Health Board 2000)

At the start of this study the national health strategy and the Primary Care strategy had set the context for community involvement. The national health strategy committed to becoming more 'people-centred with the interests of the public, patients and clients being given greater prominence and influence in decision making at all levels.' Action 52 stated that,

> Provision will be made for the participation of the community in decisions about the delivery of health and personal social services (Department of Health and Children 2001c)

Action 19 of the Primary Care strategy states that,

> Mechanisms for active community involvement in Primary Care Teams will be established (Department of Health and Children 2001a).

While community involvement in Primary Care Teams was advocated there were few if any such teams operational at the time the policy was written. Nevertheless through this and later documents it was evident that the point of connection for community involvement as far as Primary Care was concerned was the Primary Care Team (Department of Health and Children 2004b).

The definition of community participation was suggestive of the community development ethos:

> A process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change' (Department of Health and Children 2003a)

A transforming health system

This study was conducted during the largest restructuring of the health services in recent times. On the 1st of January 2005 the Health Service Executive replaced the Regional Health Boards and a number of other agencies. This restructuring also removed the mechanism for representative democracy through the Health Board system (Department of Health and Children 2003a).

The reform programme was initiated in 2003 to address difficulties within the existing health services. The strategic direction of the reform programme was guided by the national health strategy (2001). This strategy had the vision to develop a system that:

- supports and empowers family and community to achieve your full health potential
- accessible fair and trustworthy
- encourages involvement,
- ensures that your views are taken into account.

The Health Service Executive (HSE) replaced the Health Board system following the enactment of the Health Act 2004 becoming the single body responsible for managing and implementing health and personal social services. It is accountable to the DOHC for the implementation of policy, as developed by the Department, and for providing expertise and an evidence-base to the Department in the formulation of public health policy. The DOHC operates within Working Groups which draw membership from a wide range of multisectoral interests and representatives, including the community and voluntary sector (McCormack 2006)
Health and Personal Social Services were divided into three service delivery units (Health Services Executive 2006): i)Population Health promotes and protects the health of the entire population ii)Primary, Community and Continuing Care (PCCC), delivers non-acute services in the community and iii) National Hospitals Office (NHO) provides acute hospital and ambulance services throughout the country.

Primary, Community and Continuing Care (PCCC) includes the provision of health and personal social services in communities. This includes Primary Care, mental health, disability, child, youth and family, community hospital, continuing care and social inclusion services. This organisation - according to groupings of people diseases and services, reflects how the health system has evolved over many years. Formerly these groups were called 'care groups' the administration and organisation of budgets and reporting of health services was done on the basis of such care groups. Primary Care and Social Inclusion are recent additions to this system and as such are itemized under 'population groups' in the 2005 HSE annual plan (Health Services Executive 2006). The CEO is supported by seven Assistant National Directors with responsibility for services to specific groups. Thirty-two Local Health Offices manage the delivery of the Primary, Community and Continuing Care Services. A Local Health Manager has

responsibility for the delivery of services, using the resources allocated and according to the agreed Business Plan for that area (Community Action Network 2007).

The transformation of a health care system from one which evolved over time to one which has been designed has been a huge challenge. The emphasis for this transformation was to build 'a fully integrated and responsive local health service, so that people are confident that the vast majority of their health needs can be provided outside hospitals'(Health Service Executive 2007).

The reduction of representation through change

Restructuring was necessary to rationalise and integrate a fragmented system (Watson Wyatt Worldwide 2003). This restructuring however has resulted in the reduction of democratic representation through elected representatives on the Health Boards. The now well know Prospectus report that recommended the structural change acknowledged that Health Board model did allow the representation of communities interests;

> '..the legislative framework provides that the interests of individuals and communities are reflected through the participation of elected local representatives in the governance of Health Boards, ERHA and the health authorities.' (Watson Wyatt Worldwide 2003)

The Brennan Report (Department of Health and Children 2003) on the other hand was in favour of keeping, albeit rationalising, the 'Board' structure as it was a 'democratic model':

> 'There was a consensus that regional Health Boards currently deliver advantages in terms of local democratic representation within the health service. We were concerned that proposals to replace the regional Health Board structure might compromise accountability for the health service and the important corporate governance roles being carried out'(Department of Health and Children 2003a)

Though the Prospectus report consultants recognised the function of representative democracy through the Health Board they did not see this as a direct means of accessing information for community members. They note that there was an absence of focus on the

'consumer'. The use of the term consumer throughout the document indicates a consumerist rather than a citizenship interpretation of the relationship between the health system and the people. It commented that;

> there are no direct means for local communities to find out what is being planned for their local health service and no consistent mechanisms for service users to feedback their views so as to influence planning decisions (Watson Wyatt Worldwide 2003).

Furthermore these consultants did not see the democratic model as a successful or desirable for health care decision making. It revealed;

> Tensions between local representation, decision-making and the delivery of national and regional strategic objectives hinder decision-making (Watson Wyatt Worldwide 2003).

Some of the negative effects of representation on the Boards through the formal democratic process were identified as a

- Predominance of local area concerns over regional interest;
- Competition between representatives on the basis of locality or professional background rather than objective need;
- Reluctance to accept evidence-based information or recommendation where it is locally unpopular, e.g. location of acute services;
- Focus on operational and short-term issues over strategic issues

The Audit questioned the effectiveness of the boards as governance structures and noted that previous reports criticised the political nature of the Boards' decision making. The minister for health in a speech to the Dáil concurred with Prospectus that centralised resourcing decision making was the way to go. His view of HSE responsibility in terms of involving publicly elected representatives was to 'provide information'. His view of the democratic input from those representatives was to 'deliver national priorities'. In short the HSE should listen to the view of the people through their public representatives but it should follow what are determined as 'national priorities'.

> 'I acknowledge that it is important that public representatives have an opportunity to articulate their views on issues at regional and local level. I intend to place an obligation on the HSE and its regional offices to appraise and inform local representatives and the public generally in relation to service plans and developments regionally and locally. But it should be noted that the emphasis must be on ensuring that democratic input at regional level is focused on the delivery of national priorities' (Minister M Martin 2003)

The Health Act 2004 mandated the that the new Health Services Executive establish mechanisms for involving public representatives, service users and other members of the public 'in matters relating to those services'. It does not seek to replace the people's representation through the democratic process but empowered the Executive with *the full responsibility for defining measures to involve communities as well as determine the level of involvement.* Empowering the health agency alone to define such measures gives it control and power to define the spaces for and meaning of community involvement in health services.

Elective representatives tend to have a local view rather than a national one as that is the basis by which they get votes (local constituents) and stay in power. The abolition of the Health Board made it possible to focus on the delivery of a national system of healthcare but it did reduce representative democracy. The reduction in representative democracy in health care decision making has not caused public outcry, neither has it gone entirely unnoticed. An article in the Irish times noted that;

> Delays in answering parliamentary questions and the failure to record answers have fuelled concerns about the public accountability of the HSE particularly given the abolition of the former Health Boards (The Irish Times 2007)

Over the course of this study, policy development has gathered momentum (see appendix VII). The first national strategy for service user involvement which was launched in 2008, was jointly developed by the medical office of the Department of Health and the Customer Services office of the HSE (Department of Health and Children and HSE 2008).

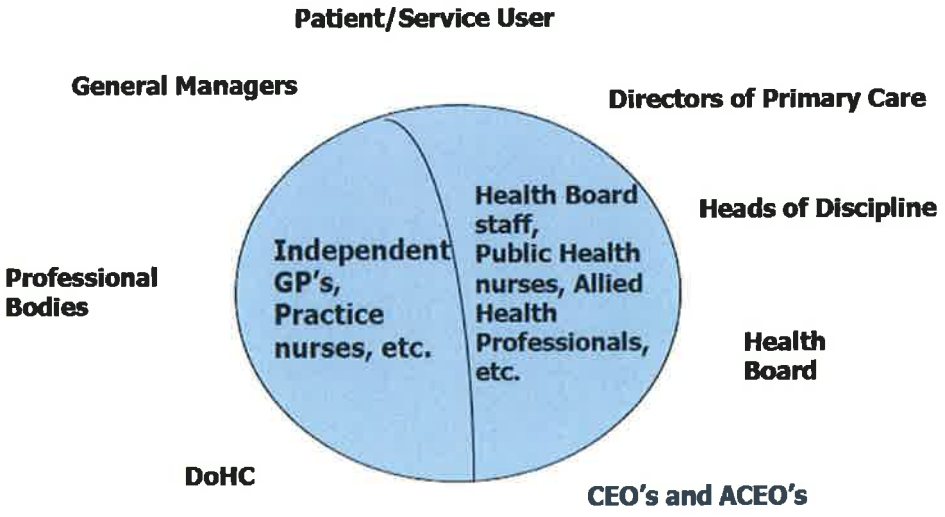
Bringing together two cultures

In October 2002, the Minister for Health and Children gave approval for the establishment of an initial ten implementation projects, one in each Health Board area. The formation of these multi-disciplinary teams brought together two distinct cultures, often working together for the first time. A review by the Office for Health Management (2004) of these 'pilot' PCTs identified challenges for the teams in bringing together professionals from distinctly different ways of working;

> The two cultures approach all levels of work differently from decision making, managing conflict and running meetings to the use of language and jargon(Office for Health Management (OHM) 2004).

It concluded that difficulties of establishing these new teams should not be under-estimated particularly within the current context of health reform. They illustrate the PCT in the figure 8 below (Office for Health Management (OHM 2004).

Figure 8 Primary Care implementation team and external stakeholders



Source:(Office for Health Management (OHM) 2004)

While the 2001 Strategy defined Primary Care and Primary Care Team composition from its perspective, GPs had a different view as highlighted in the introduction (page 21). The ICGP and IMO document described a 'core generalist team' as consisting of the General Practitioner, the Practice Nurse, the Public Health Nurse, and 'possibly' the Community Pharmacist. They advocated that this team would serve a common patient list' (ICGP & IMO 2001). This fundamental difference in perspective between the GP and health authority perspective was not addressed at a policy level.

The evolution of 'two cultures'

Irish general practice has its origins in the poor law system established in the middle of the nineteenth century to provide relief to the poor and destitute. This was funded through raising local rates per district which provided services to those in workhouses that were built and run harshly with the specific intention of discouraging use. Eventually rules were relaxed and 'outdoor' relief was provided outside the confines of the workhouses. District medical officers (DMOs) were responsible for eligible people within districts. Initial GP services were geographically based and patients had no choice of doctor. GPs were salaried and worked from rudimentary dispensaries. Patients who could not travel to the dispensary were visited in their own homes. Only in the 1950s were patient lists introduced (Boland 1997).

GPs supplemented their salaries by opening private practices often in their homes. The lack of patient choice of GP and the discrimination between paying and non-paying patients regarding where they were seen led to the white paper on the Future Development of Health Services of 1966. This proposed the replacement of the dispensary doctor service with a service involving private practitioners and based on the principle of choice of doctor. After considerable negotiation the General Medical Services Scheme (GMS) came into operation in 1972. Eligible patients were free to choose from a panel of GPs. GPs were 'required' to see private and public patients at the same premises (personal communication Prof Shannon, Head Department of General Practice, RCSI; (Howie and O'Cuinneagain 2002).

Traditionally GPs operated in single practices and were seen as local, independent business people. They hired their own staff and were largely autonomous in terms of service delivery and decision making. Even with the increasing trend towards group practices this culture has remained relatively unchanged (Office for Health Management (OHM) 2004).

Lack of integration within the community services and between the GP and Public Health Nurses (PHN) was seen as a major challenge. Prior to the 2001 national strategies the western Health Board strategy (Western Health Board 2000) recommended the division of the area into Primary Care catchment area, and establishment of Primary Care teams on a pilot basis (Western Health Board 2000). The Eastern Health Board framework planned to address integration through partnerships between professionals working in the community. The North Inner City Partnership in Primary Care (NICP) was developed as one such partnership (Eastern Health Board 1999).

Section summary

The Irish context sees Primary Care only being formally defined at a national level in 2001. Implicit policy sees community services providing aspects of a social determinants approach to health care. Explicit policy to involve communities developed after the development of the national strategies. The approach to community involvement resonated with the community development approach. Restructuring of the health services was based on the consumerist rather than citizen model and resulted in a reduction in representative democracy. This approach does not sit well with the community development model.

Health authority definitions emphasise professional multidisciplinary Primary Care Team working with an emphasis on working with communities. Prior to this, General Practice and community services were very distinct and separate services conceptually and practically. Attempts at implementing the Primary Care Strategy which see a fundamental shift in how Primary Care is provided and indeed what it comprises were made through ten implementation projects nation-wide. These projects represent the coming together of two cultures, community services and General Practice that evolved separately over the previous fifty years. In addition to the bringing together of these separate 'cultures' community too are to be involved. In areas such as my study area (were no implementation project exist) Health Boards tried to tackle integration. The North Inner City Partnership in Primary Care (NICP) was the result of one such effort.

Chapter 5 A deprived inner city

This study was located in the catchment area of the North Inner City Partnership in Primary Care (NICP) (appendix I). This area contains some of the most deprived areas in the country. Lack of choice in health services accompanies the materially poor. Material wealth creates choice as services will increase in proportion to the articulation of need which is facilitated by the available money. This articulation manifests itself in market supply and results in the provision of services to meet that demand. 'Need' in the context of deprivation is a silent demand as articulation of the need cannot take place without the attendant money. Without this articulation, services that exist remain unaware of the needs unless they are proactive in investigating that need by engaging with that part of the population that are marginalised and where that demand is 'silent'. This 'silence' I will call 'marginalised voice'. This will be dealt with in later chapters. I developed a relative index score (described below) to determine which areas in the study area were most deprived in terms of health and social indicators in order to highlight areas which may contain 'marginalised voice'.

A Local Authority flat complex in the north inner city Dublin

The analysis below shows a wide variation in health and socio economic indicators across the NICP area. It shows an identifiable link between health and deprivation and shows that 'black spot' areas are identifiable. This is the first time such an analysis had been conducted for the NICP area. It showed that health services had as yet not been planned on the basis of a local needs analysis, or a review of deprivation.

I feel it is important to stress the difficulty I had in accessing health statistics for the study area. This difficulty in itself serves as a barrier not only to the organisation of a health system based on need as recommended in health policy (Dept. of Health and Children, 2001) but also to the involvement of communities in health.

Health and deprivation in the NICP area

Dublin's inner city has experienced great physical and social change over the last decade with an increasing population size, increasing immigration, and a vast amount of new building developments. Through the seventies and eighties the population declined as people with skills and money drifted away from the centre of the city. This was accompanied by a decentralising industrial, commercial and service base (Connolly 1997). The extent of the urban renewal over the previous 10 to 15 years had been intense and at the time of my field work there was nowhere in Dublin's inner city one could stand without counting at least four construction cranes nearby. Population movement had been remarkable. There was an influx of professionals able to afford the newly developed apartments. At the same time there was some displacement of local authority tenants into Dublin's sprawling suburbs. Nevertheless large geographical black spots of deprivation were still to be found in the inner city. Between 1996 and 2004, development involving about 18,500 residential units resulted in considerable growth of population in parts of Dublin's inner city. The property building reached its peak towards the end of 2006 after which the building boom experienced a sudden crash. The fact that Dublin's inner city could no longer be considered deprived in its entirety had led to false conclusions; that deprivation has been eradicated. A picture of inequality *within* localised areas has been attributed to the increase of private housing development and the consequent location of affluence next to poverty (Haase 2008).

The North Inner City Partnership (NICP) in Primary Care's catchment comprised a large geographical space approximately 3km by 4kms with a population of 106,932 according to the 2002 census. Only a segment of this area could be accurately described as the inner city. The NICP area boundary lines were not coterminous with any other administrative boundaries[4]. I collated and mapped data from the CSO, HSE, Cancer registry and the Central drug treatment list for the 35 electoral division (ED)[5] areas comprising the NICP area. The names and positions

[4] Up until 2005 the basic spatial unit for administration of the system outside the hospital was the community care area (CCA). Except for the Dublin area these areas roughly corresponded to the county boundaries. In and around Dublin there were 8 CCAs. In 2005 with the establishment of the Health Service Executive (HSE) which replaced the regional Health Boards (HB), these CCAs were renamed Local Health Offices (LHOs) and LHO managers appointed to be responsible for Primary Care services which would be delivered through them. The NICP area crosses over parts of two different LHO areas, North West Dublin (previously CCA6) and Dublin North Central (CCA7)

[5] The electoral division (ED) area is the smallest administrative unit for which CSO data was available

of the EDs contained in the NICP can be found at appendix III. The mapping and analysis I present below had never been aggregated for the NICP before.

Population & age distribution

Between the 1996 and 2006 census the population in the NICP area increased by 17% (figure 9). Growth however has been hugely varied with some 'poorer' areas experiencing an almost doubling in population over the decade. Lower rents as well as the opportunity for commercial activity have attracted foreign nationals to some areas resulting in relatively high proportions of this group clustering in specific areas (e.g. North City: 40% 'foreign nationals').

The NICP area has a low child (0-14yrs) and high adult male (25-44yrs) population (figure 9). Once again however there is huge variability with peripheral areas having relatively high older populations (Cabra East, Ashtown B and Clontarf West E showing over 20% over 65 years.) More women are represented in the over 65 year old age group (figure 10) reflecting the higher mortality among men in this age group (Balanda and Wilde 2001b).

Figure 9 Population change in the NICP area compared with Dublin City and the State

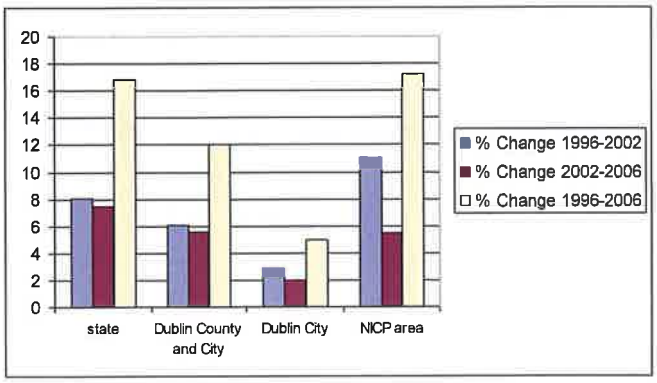
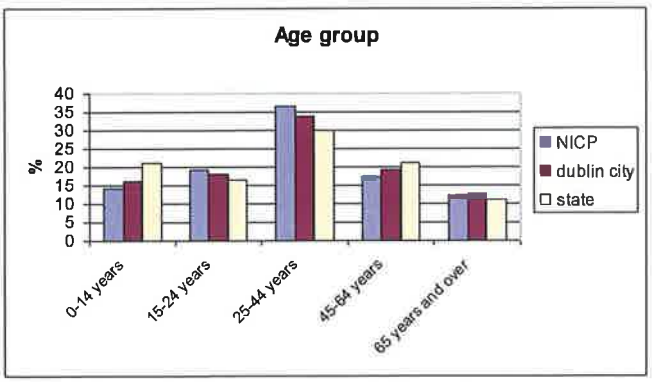


Figure 10 Age distribution in the NICP area compared with Dublin City and the State



Unemployment& Social Class

Reflecting national trends, there had been a general downward trend in unemployment[6]. The relative unemployment rates between the NICP area (12%) and the State (4%) is significant. In some EDs unemployment is over 20% (Mountjoy A, Mountjoy B, Inns Quay, Ballybough A Ballybough B). The darker shades in the figure 11 indicate the areas of high unemployment.

The socio-economic profile which is based on classification of males' employment showed lower proportions of the higher socio-economic classes 1&2 (26%) than the state (31%). Predictably, when focusing in closer to the level of the ED, bigger differences in Social Class grouping are seen. The areas considered 'better off' locally (Botanic AB&C and Clontarf D &E) show much higher proportions (40-60%) of Social Class 1& 2 than those considered 'poor' areas (Mountjoy A 13% & Mountjoy B 14%).

The General Medical Services Scheme (GMS) provides a 'medical card' to people deemed entitled to access to free health services including Primary Care Services. Eligibility is assessed on the basis of income, thus is often regarded as an indicator of low incomes. This is problematic in so far as it assumes equal access to the assessment process for obtaining the card. Other barriers to entitlement exist including inherent problems with the application and renewal process(O'Carroll and O'Reilly 2008c). This may explain why the proportion of the NICP population covered by medical cards was lower at 27% in 2003[7] than that estimated for the country as a whole (30%) (Tussing and Wren 2006). As seen in figure 12 some EDs showed high medical card coverage (40%) (Ballybough A and Mountjoy A).

The majority (24) of the 35 EDs included in the NICP area received very poor scores (either a 9 or a 10) on the *SAHRU National Deprivation Index*[8]. The inner segment of the NICP with parts of Cabra were identified as very deprived according to this index.

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[6] Unemployment rate is total unemployed population (unemployed and first time job seekers) as a percentage of total active labour force (at work, unemployed and first time job seekers).

[7] This is based on data supplied to the NICP in 2003

[8] Small Area Health Research Unit National deprivation index. The SAHRU index is based on CSO Small area population statistics at Electoral division level it combines unemployment, low social class, local authority housing, car availability and overcrowding. '1' denotes a relatively affluent area while '10' denotes the most deprived areas. This analysis was bases on the 2002 census.

Mortality & Morbidity

Health data at the ED level was unavailable or too old to use. There was no systematic collection and collation of morbidity data at the Primary Care level by the health authority. There is no reliable health data collected by locality. The only health assessments that took place were carried out by community groups and independents, despite there being a national strategy commitment to plan services on the basis of assessed need (Department of Health and Children 2001a). Cairde (2006) identified stress, anxiety and depression as a significant contributor to poor health among ethnic minorities (Sanders and Whyte 2006). A survey of elderly people saw circulatory problems, arthritis and respiratory problems as the leading 'illnesses' in the 47% of respondents who said they had one (Rourke 2005). A survey of the health of the homeless found a significant rise in drug use and associated morbidities compared with a previous survey. Blood borne infections were prevalent (HIV (6%), Hepatitis B (5%), Hepatitis C (35%)) and there was a significant rise in depression (33% vs. 49%) and anxiety (28% vs. 40%) (O'Carroll and O'Reilly 2008b).

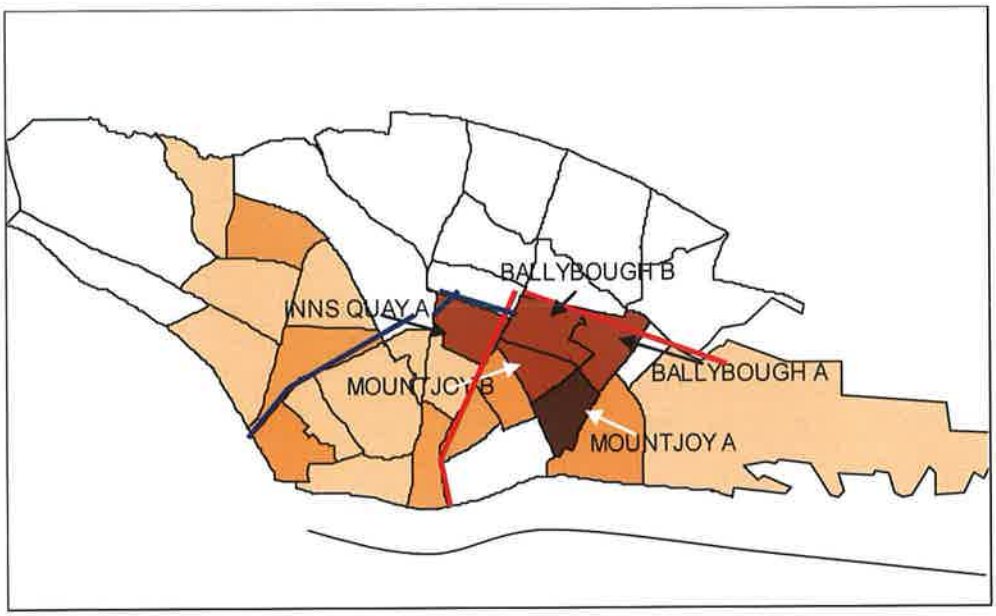
The most recent data on mortality which is geo-coded was '1994 to 1998'. The Standardised Mortality Rate (SMR) [9] is significantly higher in all, bar four EDs when compared with the East Region health authority (ERHA) area as a whole. The darker shades in figure 13 show areas of higher SMRs. The causes of death in Dublin as a whole are similar to the rest of the country with leading causes being circulatory, neoplasms, respiratory, and injuries. Data was not available for cause specific mortality by ED.

Drug addiction is a major cause of poor physical and mental health in Dublin's north inner city. The number registered for methadone treatment is sometimes used as a proxy for opiate use in the community. A total of 1244 registered on the Central Treatment List (CTL) had an address in the NICP area. Nationally at this time there were about 8,364 people registered on the CTL as receiving methadone(Drug Treatment Centre Board 2004). Figure 14 depicts a serious drug problem, particularly in the North East Inner City (NEIC) area with identifiable black spots. One in every 17 adults in Mountjoy A was registered on a methadone programme.

[9] The data shown is Standard Mortality Rates; this means it is comparable even though populations may have different age sex structures. The reference population against which all EDs above are compared is the ERHA population; this has a SMR of 100. Data Source: The Health Information Unit, HSE: Health Intelligence and Population Health 2005

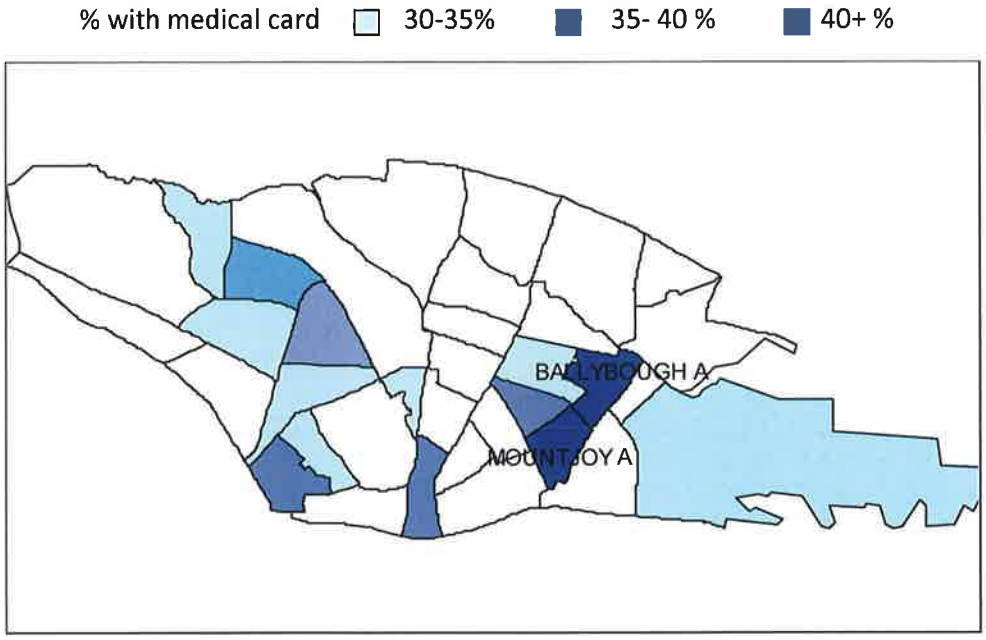
Figure 11 Proportions of ED populations unemployed (CSO, 2002 census)

% Unemployed 10-14% 15-19% 20-25% 25%+



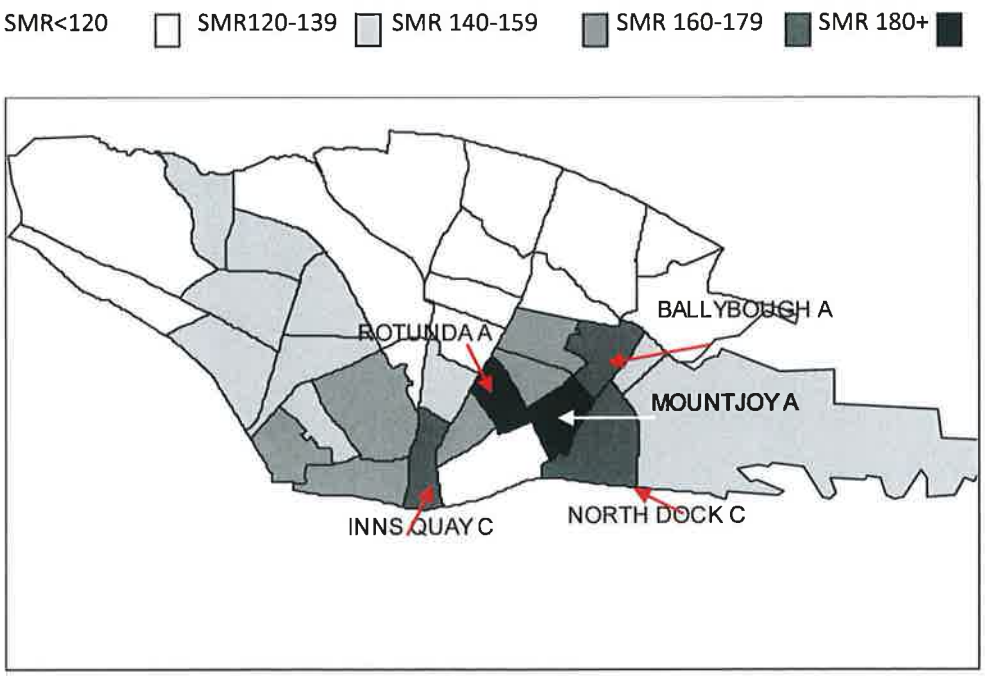
Data from 2002 census: map created by F.O'Reilly 2004

Figure 12 Proportions of ED populations holding medical cards 2003



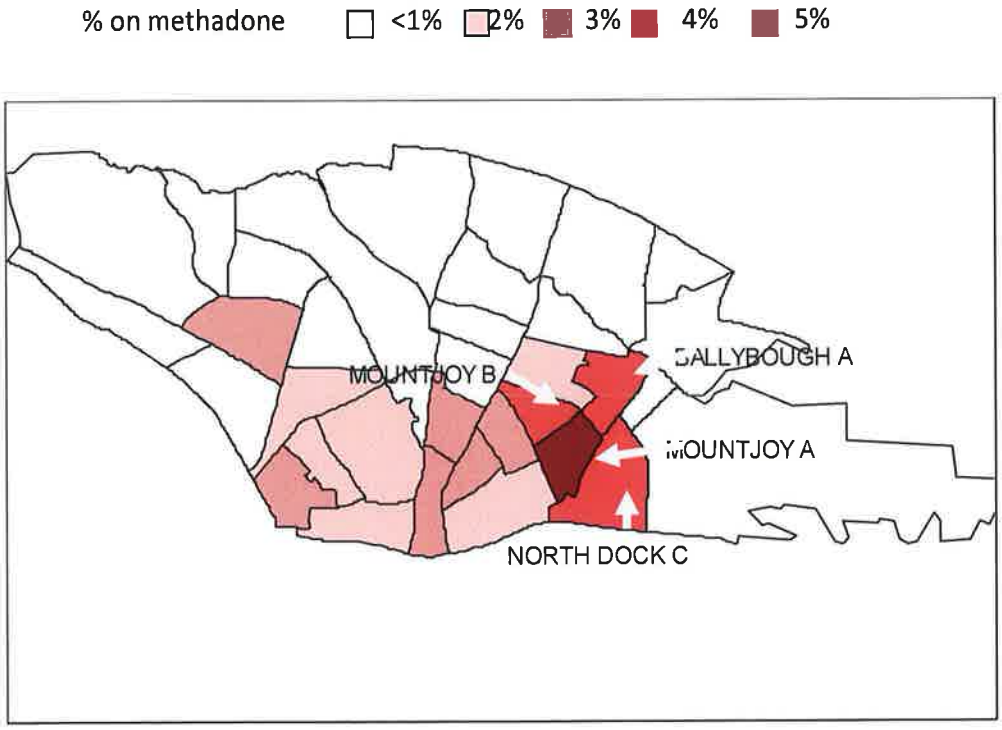
Data from NICP: map created by F.O'Reilly 2004

Figure 13: Standardised Mortality Rates (SMRs) by ED North inner city area



HSE 1994-98 data: Reference population ERHA =100. Map created by FO'Reilly

Figure 14: Proportions of ED populations registered for methadone treatment



Data Source Central Treatment List 2004: Map created by FO'Reilly

Black spot areas

Though there have been improvements on most socio economic indicators, for example the reduction in early school leaving, the increase in labour force participation rate[10] and the decrease in unemployment rate,[11] the inner segment of the NICP area in particular is relatively more deprived than the outer segment.

This inner segment as an identified 'deprived area' falls within other 'partnerships' established to focus on socio and economic regeneration i.e. Dublin Inner City Partnership (DICP) & Revitalising Area Planning Investment and Development (RAPID)[12]. As an area with much drug

[10] Labour Force Participation rate is the total labour force (those at work, unemployed and first time job seekers) as a percentage of the population aged 15 years and over.

[11] Unemployment rate is total unemployed population (unemployed and first time job seekers) as a percentage of total active labour force (at work, unemployed and first time job seekers)

[12] The RAPID (Revitalising Areas by Planning, Investment and Development) programme, launched in May 2001, aims to ensure that priority attention is given to 25 disadvantaged urban areas by relevant Government Departments, Local Authorities and statutory agencies (within the context of the National Development Plan).

abuse the North Inner City Local Drugs Task Force (LDTF) was established as part of the state, voluntary and community response to problematic drug use. The inner segment also has a strong community organisations structure which fall under two community network organisations Inner City Organisations Network (ICON) on the east and North West Inner City's Areas Network (NWICAN) on the west.

I further analysed these indicators across the NICP area to identify areas which scored badly on a number of indicators relative to other EDs. To do this I created a relative index score which identified 'black spots' of health and deprivation within the inner segment of the NICP area. I did this by imposing arbitrary cut-offs on indicators to signify high or low prevalence (e.g. high prevalence of drug users or low medical card coverage) for each area relative to other areas. I then combined the number of indicators on which an area scored relatively poorly, to give a combined score. If an ED had achieved a 'high' level on one indicator it received a score of 1, if it received a high score on 2 indicators it received a score of 2 and so on up to the highest possible score of 9. I judged areas with the highest combined scores as 'black spots' in terms of health and deprivation (appendixIV). This rudimentary method of pinpointing highly deprived areas indicated Ballybough A had the highest combined score (9) followed by Mountjoy A (8). Both of these areas were in the east of the inner city. In the northwest inner city Arran Quay D and Inns Quay C both received a combined score of 6 each. Each of these four 4 EDs showed high mortality, high proportion of the population being treated for opiate addiction, and high proportions of the populations renting from the local authority.

Conclusion: black spots of extreme health and socioeconomic deprivation

This preliminary mapping and analysis provides a description of the NICP area in terms of deprivation and health. The NICP area arbitrarily defined across two separate health authority administrative areas is an area of varied affluence and poverty existing in close proximity. The inner segment of the area is generally more deprived than the outer segment. However even within this segment it is possible to identify black spot areas based on health and socioeconomic data (Haase 2008). Area based analysis tends to hide such black spots due to the close proximity of rich and poor.

Chapter 6 Local Primary Care Provision

In this chapter I look through a professional health lens at Primary Care and chose the Public Health Nurse (PHN) and the General Practitioner (GP) to illustrate Primary Care practice. The GP and PHN are recognised as the 'lynch pins' of the Primary Care system (Department of Health and Children 2001b;ICGP & IMO 2001). I do not intend to represent the entirety of professional Primary Care practice, but rather I hope to illustrate some of the integral problems which result in a disparate range of services, rather than a system or entity into which community, people, or users can become easily involved.

A health authority health centre in inner city Dublin. (2006)

Primary Care Professionals

The health authority employs a range of health professionals to provide services in the community including Public Health Nurses, child health workers, community welfare officers, speech and language therapists, social workers, physiotherapists, occupational therapists, psychiatrists and home helps. It also contracts services in the community from self-employed health care providers namely GPs, Dentists, Opticians and Pharmacists. It contracts or funds community and voluntary groups to provide services in the community, such as after schools projects, carer organisations, homeless services and drugs projects.

The Primary Care services are provided in the Health Centre, the home, the pharmacy, General Practices and dentists' surgeries and other community settings. A system of Primary Care assumes that all these professionals in these sites are in some way working together and towards a common goal. This was not the case. The Primary Care strategy (2001) recognised the disparity of the system and attempted to counter this through the establishment of Primary Care Teams (PCT) and networks. A team comprising of GPs, nurses, occupational therapists, physiotherapists, home helps, health care assistants, social workers, and administrative staff all of whom would cater for populations of 3000 – 4000 people within a framework comprising of community welfare officers (CWOs), speech and language therapists, psychologist, pharmacist, dentist, chiropodist and dieticians. This organisation would indeed have the necessary requirements to be envisaged as a 'system'. Teams would work from

purpose built sites called Primary Care Centres. While on paper this looked like a viable system, it bore no resemblance to the 'system' of Primary Care I observed during my field work in the north inner city from 2004 to 2006.

Though all the categories of professionals were present within the NICP area they were not organised into PCTs. Nor were there adequate numbers to organise on the basis of the Primary Care strategy. Indeed the recommended levels of GPs per team (4) would theoretically provide the population of the NICP with 109 GPs. Though it is difficult to map the actual number of GPs providing services to the NICP population the majority were assumed to be registered as part of the NICP. These were 56 GP's in 30 private practices scattered throughout the bounded area shown in the map at appendix I

There was no system in place which would make it possible for the required categories of Primary Care professionals to work together. Two fairly obvious obstacles to the development of a working system were i) the lack of Primary Care Centres to house Primary Care Teams (PCT) and ii) the fact that the core members of the proposed team, the GP and the PHN, provided services to different populations of patients. The PHN was allocated people within specified geographical areas while the GP served patients who choose to register with him whether they paid for the consultation themselves (approx. 70% of population) or had access to free health care based on a means test (approx. 30% of the population)(Tussing and Wren 2006). The latter form the GPs' General Medical Service (GMS) list. The health authority paid the GP a capitation rate for those on his GMS list.

The Health Centre (marked in red on the map: appendix I) was the property of the health authority and generally housed the direct employees of the health authority. The following excerpt from my field notes gives a picture of the health centre in a very deprived area of the NICP area:

> From the outside the Health Centre is uninviting, run down, with bars on the windows. Across the road is an ugly block of derelict flats. They had been almost completely emptied and boarded up. A number are burned out. Immediately inside the health centre is a lobby. On the right a reinforced glass screen, behind which security guards sit in a sizable room. A hatch in the glass allows for communication with the guards. This lobby leads to a very large waiting area on the left and a locked door with security code to the right. In the waiting room seats face four doors. These doors lead to small rooms

> in which Community Welfare Officers (CWO) sit behind reinforced screen. Two treatment rooms lie to the back of the waiting room. These are used two days a week for the baby clinic and on two afternoons for 'needle exchange': a harm reduction service for drug users. The locked door with the code leads to another small area then another locked door leads up the stairs to the nurses' office and the kitchen. The Health centre inside is clean and freshly refurbished. In terms of space it is dominated by the Community Welfare Officers' offices (Field notes: November 2005).

The GP is a self-employed professional and is responsible for buying, renting or leasing his or her own premises in which services are provided. Practice Support payments for use of premises, staffing, and pensions were available to GPs and proportional to the number of General Medical Services patients registered with a GP. The following is a description of a GP surgery in a deprived area of the NICP area:

> The building is an old Victorian house with 4 floors and a basement. Once in the front door there is a small corridor that is usually so full of people it's hard to open the door wide. There is a stairs to the left, a narrow hall next to it leading to a small waiting room. There are two rooms off the small lobby at the main door, one used by the Practice Nurse and one by the GP. There is a disabled access toilet in between. Immediately on the right, on entry there is the reception area with barely enough room for the 2 receptionists behind a constructed partition with a hatch. Up the stairs, on the return there is another small office which overlooks the waiting room. Up another set of stairs are two offices one used for one of the secretaries for scanning reports from hospitals into the computerised patient filing system and for staff meetings. The other room is a large consultation room where the second doctor sits. The practice building has 2 further floors from which independent counsellors work and a basement from which a HSE addiction service is run. The practice patients with opiate addiction problems are seen in the HSE clinic in the basement by the Practice GPs on one morning per week. Original paintings and sculptures hang on the walls of the various offices and waiting area (Field notes: June 2004).

The development of infrastructure to establish single site Primary Care Sites was seen as central to the working of the new model of Primary Care in the long term. However in the short term the strategy acknowledged that services operating from multiple sites would be

necessary (Department of Health, 2001 p32). Infrastructure in terms of health centres and General Practice facilities within the inner city was grossly inadequate.

The Public Health Nurse: involved in a deprived community

Mary is a Public Health Nurse (PHN), her 'patch' is a deprived area of the north inner. Unlike other health professionals working in the area, PHNs are assigned to areas. Street by street the area is divided up and covered by the PHNs working from the local health centre. I shadowed Mary as she visited people in their own homes and present a description of a Mary's working as the Preface to this thesis.

On certain clinic days people come to the health centre, usually with their children, for developmental assessment and vaccinations, or for dressings. The PHNs is notified every time a baby is born and is required to visit the new mother and baby within 48hrs of the birth. Similarly the PHN is notified when someone requiring follow up care at home is discharged from hospital.

Mary's visits took us into a homeless hostel, an asylum seekers hostel and into family homes. Mary did dressings, examined new babies, gave advice, listened and laughed. Many times along the way Mary was stopped in the street by people to talk or for her advice on something. It was difficult to count how many 'patients' she saw as it was difficult to identify people as patients. It was difficult for me to ascertain their diagnoses. As such unlike the ways in which medicine is practiced, Foucault's "medical gaze" which signifies the way the patient's body was separated from the patient's person and agency, was not evident in the way she worked (Foucault 1973).

The nurse did her work in the homes of the people and along the streets in the local area where they lived. She also visited schools, day care for elderly, a reception centre for asylum seekers as well as the long term care centre for the homeless. As such she engaged with community groups and voluntary sector organisations providing many of the services. She knew many of the families through visits after a child was born and was familiar with their social circumstance, living environment and other family members. Her role meant she was involved in the community and so was sensitive and aware of, the health needs of the community in which she worked.

The people in her area went to different doctors. She had not met them all. There was one or two with whom she had a good relationship and with whom she had done joint visits, though she considered these the exception.

A one doctor General Practice in north inner city Dublin.

The General Practitioner: treating medical problems

The GP I shadowed for a week was unusual in that he provided on site consultations to a homeless hostel (in the same area as I had visited with the PHN) once per week and supported nurses in hostels by phone. The health authority paid the GP to provide these services:

> Within minutes the GP arrived on his bicycle. We went into the hostel and found the nurse in the 'clinic'. This was one room with a desk, computer, table, and treatment couch, a sink, dressing trolley, cupboards and shelves. This hostel was the only one in Dublin with a nurse providing services seven days per week. It also provided chiropody and GP services twice a week and psychotherapy and acupuncture once a week. The GP provided 24 hour phone support to the nurse who saw and treated homeless patients. The nurse greeted us and offered us tea.
>
> Between 8 and 9 the GP and nurse saw 4 patients, this they felt was very few. One of the men, a drug user had a vicious looking skin problem all over his body as well as a leg ulcer. The GP arranged for a referral to the Mater hospital. Another man had a cough and another seemed to have pulled a muscle under his arm. This man had spent his first night homeless due to relationship breakdown and 'the drink'. The fourth man came for a renewal of his prescription for anti-depressants, was no longer homeless, and was now working (Field notes, November 2005).

Unlike the PHN there were a number of practices which could be described as 'dividing' according to Foucault's (1984) ideas of how people become subjects. Patients were clearly identified as 'patients', they were separated from natural habitat and others and seen in a special (consultation) room.

The GP sees and treats patients alone. On occasion he sends one into the practice nurse or consults with her for results. For some patients he calls the liaison nurse in the Hospital to have notes checked or consults with a hospital doctor or psychiatrist. The GP exercises what McDonald (1994) referred to as the 'engineering model' in which the patient is removed from a situation of control (own domain), where disease tends to be as something 'objective' in the individual, but separable from them, waiting to be identified and dealt with by the medical profession.

A consultation I observed with the GP shows how a GP, isolated from the other health services, is ill equipped to resolve social problems which may exacerbate underlying medical issues:

A woman enters the consultation room and sits down;

"how'ya doctor".

He greets her and says;

"give me a second".

He pulls up her file on the computer; very quickly he looks at it. He looks at the skin problem on her face which she has come about. He tells her she has dermatitis and he prescribes a shampoo cream and explains how she is to use it.

They sit close facing each other. He asks her to repeat the instructions. She's not clear on them, he repeats them. Then he says,

"how is life?

"Not great" she says.

He talks about a letter he had written previously regarding her depression. She's out of work and can't go back (I'm not sure if this is due to her depression or because she is looking after her aunt who is 86 and who she considers her 'mammy' as she has been with her since she was a baby). She says she is off work for two years. The GP asks her about the Carer's Allowance, has she applied for it? She's a bit sceptical,

'I don't know anyone who's got the Carer's Allowance'.

He advises her to talk to the Welfare Officers. He asks her if she knows where to go to find out and she says

"Is it the Community Advice Centre, the MARKO?" She asks

He said it's probably the Citizen's Advice Bureau in the Community Centre, but that he'll look it up for her. Then he starts to look for the information by browsing the internet (Field notes October 2005).

In the consultation above the patient is visiting the GP for a medical problem however at the same time her depression (the GP informs me later) is potentially exacerbated by a social problem about which the GP alone is poorly equipped to tackle in a ten minute consultation. The de-link between the GPs private practice and the health authority funded services meant that GP did not have easy access to the range of personnel who could potentially intervene to provide social supports such as home helps, family support, social workers, community welfare officers, local support networks and groups.

The link between medical need and social need in particular areas was described by the Community welfare Officer (CWO) who felt that specifically in these areas a 'community approach was needed'. CWOs originally from the department of Social Protection , were seconded to the health authority and were situated in local Health Board clinics. This CWO linked financial problems to medical problems through 'stress';

"no matter what health service you put in and the most dedicated, you'll know the staff here are very dedicated, if people are financially insecure...they're not going to be healthy. They'll borrow money from the money lender at an interest rate of 39% per week for the kids at Christmas but the mothers will go without and the stress that causes must affect your health" (Interview with CWO)

Barriers to a system

A system can be broadly defined as an 'integrated set of elements that accomplish a defined objective' (SE Handbook Working Group 2000). In most systems a degree of relationship between the parts is assumed. The WHOs definition of a health system emphasizes the common purpose rather than the degree of relationship: A health system is the sum total of all

the organizations, institutions and resources whose primary purpose is to improve health (WHO 2005). In this regard there was a lack of a common purpose or understanding of health and the causes of ill health among the GPs who treated patients medically and the health authority staff like the PHN and the CWO. Unlike the GP's the health authority staff like the PHN and the CWO were more cognisant of the social determinants of health. See below.

Another conceptualization of a health system emphasizes the importance of the interconnectivity of the parts. Hsiao (2003) defines a health system as;

> 'a set of relationships in which the structural components (means) and their interactions are associated and connected to the goals the system desires to achieve (ends).'

It is not hard to see through engineering how precision in design can produce a good working system where parts do not necessarily have to 'talk' to each other. However in a system where parts have developed some independence over time, lack of inter-component communication means that not only does the system fail to work, but the system fails to exist, even as a system.

In overall terms the largest obstacle to the workings of a Primary Care system, is that the component parts did not 'talk' to each other. This was not because there was no will but rather there was no mechanism to do this. GPs remained isolated from health authority services in the community and people had to go different places in a fragmented system for different aspects of Primary Care services. These themes are discussed below.

Differing understandings of health

Unlike the medical approach to Primary Care described by McDonald as the 'engineering model', aspects of the Primary Care services provided by the health authority showed a very different understanding of health. The health authority is a significant financial supporter of the community and voluntary sector. It provides grants under Section 26 (Health Act 1970), Section 65 (Health Act 1953), and Section 10 (Childcare Act 1991) to bodies that provide a service similar or ancillary to a service that the Health Board provide. Over €100 million is distributed under this scheme annually (Weafer and Weafer 2004). The Irish Health system also administers the supplementary welfare scheme through the Community Welfare Officers (CWOs) it employs. As seen in the description of the health centre above, the majority of floor

space was given over to the CWOs, reflecting proportionally the scale of the deprivation in community it served. A senior CWO in a north inner city health centre explained the importance of the role of CWO particularly in areas of deprivation.

> "Welfare is the safety net of society. The State dictates a person will have a minimum amount of income. Any person who falls below that for whatever reason, a CWO comes in and provides a safety net. It's a brilliant service, 'cos it's instant. We have a chequebook, we can go in and we can resolve that problem. It can be for many reasons. You lose your job, you apply for State intervention, unemployment benefit or unemployment assistance. It takes time to get through. It can take up to 8 or 9 weeks and you won't get paid in that time, so you come to the Welfare Officer and we pay you pending that situation. You may be sick but have not enough insurance payments to qualify you for payment. It's called sick note benefit. We step in. You may have a part-entitlement to it. We bring you up to scale. That's one part of our job. Another part of our job is to meet unforeseen need, for a group of the population who haven't got the income to meet that need"

This CWO described his links with the GPs and PHNs in the area as informal. He gave examples of when he would contact a GP if he was concerned about a client and knew the GP. He also said the PHN and CWO would refer clients to each other. Significantly, he did not receive referrals from GPs.

Lack of 'inter-component communication': talking

The reason for the de-link between the health authority staff and the GPs can be seen as influenced by how the services developed separately (Boland 1997;Howie and O'Cuinneagain 2002) differing cultures (2004), the lack of GP access to existing services and by the differing patient populations. Some GPs did not believe that the health authority community services existed in adequate supply or at all. They aimed to be as autonomous as possible within their practices. One GP explains his frustration in trying to access a social worker for a family at risk:

> "I had a guy who came into me insensibly stoned out of his mind on coke or whatever, I'd say he had taken a mixture, his wife had gone off with his friend the night before and she wasn't coming home for a few days, and she was right because he wanted to beat the shit out of her, and he had five children and he said "I can't handle them", you know, and he was right, including the baby he was carrying, and I rang the Social

> Worker and she said are you saying there is abuse happening here, and I said no, thankfully the man is coming in before the abuse happens and ah, she says well if there is no abuse happening we have no jurisdiction on this" (Interview with GP from NICP)

The Primary Care Team envisaged by the Primary Care Strategy was to be equipped to deal with both the medical and social needs. In the example of the Primary Care model in action the nurse, during a vaccination consultation, utilised the contact with the vulnerable family to intervene on a number of levels(Department of Health, 2001p 25). These interventions were made possible by the nurses' knowledge of local voluntary and community structure, access to the CWO's appointment schedule, and autonomy to manage the child's enuresis. However, this is a hypothetical scenario. In practice though, the CWO is often operating from the same building in which a team approach to care is not the norm. Nevertheless easy access by the PHN to the CWO is facilitated by close physical proximity but this is not shared by the GP's, many of whom are not aware of the services the CWO provide.

The reality on the ground was that a Primary Care Team approach described in the 2001 strategy was not yet in operation at the local level in deprived inner city areas of Dublin. Structural barriers included lack of joint premises, and lack of shared client populations and patients. Any team approach referred to in this study was dependent on individual nurses and doctors going out of their way to find each other. Some met and occasionally jointly assess a patient. The GP was better linked to information on social welfare provisions for his patient through cyberspace than to health authority staff situated in health centres or indeed to the numerous community services funded by the health authority.

Isolation and fragmentation

Isolation of GPs and the fragmentation in the delivery of Primary Care services has been recognised by both the health authority and the Irish College of General Practitioners (Boland 1997;Department of Health 1994b):

> General practitioners and other Primary Care staff often work in isolation and communication between the different Primary Care service providers is not optimised. This leads to public services that are poorly integrated and fail comprehensively meet the needs of individuals and communities in an appropriate Primary Care setting (Boland 1997)

Serious barriers existed to the implementation of such an approach including the fact that for the GP, time was quite literally money, and time consuming home visits did not make financial sense. In general communications between GP and the many PHN who saw his patients took place by phone. Because patients can choose a GP's but not a PHN the GP patient lists bleed across many different PHNs areas. Likewise, families in any one PHN area are likely to have a range of GPs. PHN and GPs were not part of same team as proposed by the 2001 Primary Care Strategy. The GP worked very much in isolation of other Primary Care professionals and services. Though there was no formalised Primary Care Teams at the time of my field work the PHN had better links with the other Primary Care professionals than with the GP largely because they used the same health centre. She also had formal and informal links with community groups in the area.

Bits of services for bits of people

I noted in a number of different Primary Care settings that I would sometimes meet or hear about the same patient without the service provider being aware the patient was attending another service. For example, Fred, a homeless man with a drug problem was seen by the addiction team in the drugs treatment clinic to receive his methadone, by the nurse and doctor in the hostel where he stayed, and by the PHN in his mother's house prior to becoming homeless, and again at the health centre afterwards. None of these Primary Care professionals had met each other. The fragmentation of the system encouraged *'bits of services for bits of people'* rather than a holistic approach. This was particularly evident in the system to deal with drug addiction where drug users were further categorised due to their addiction status. A specific system for the treatment of opiate addiction had been established in 1998 (see chapter 7). Under this system most people in the north inner city with an opiate problem were treated in addiction clinics and are expected to have a separate GP for general care.

The lack of a shared information system among the health care providers involved with the same individuals undoubtedly leads to duplication and overlap as well as opportunity costs. The following illustration occurred while shadowing a GP at his General Practice:

> The receptionist came in and said that there was a girl in the waiting room and she did not seem happy about the girl or the medication she wanted. I recognised the name of the welfare officer who had referred the girl as one of the team for homeless people. I immediately knew who the patient was. The girl was recently an inmate in

> the Central Mental Hospital. She had serious psychiatric and addiction problems and was potentially very dangerous. (Field notes: February 2005)

I was aware that because my field work had taken me to many different Primary Care sites I had more information than the GP did about this patient. Ideally the components of the health system would share an information system which would allow information from different sites involved in care of one patient be shared. Boland (1997) described the iinformation and communications technology as very underdeveloped:

> The potential of ICT to inform the public and to significantly impact on service delivery, especially the sharing of information between practitioners and continuity of care plans for patients across programmes of care, needs to be realised.

Conclusion: the non-system approach

If was difficult to identify a comprehensive Primary Care entity, system, or unit, at the local level. This makes it even more difficult to conceive exactly 'what' communities could become involved in at the local level. Primary Care was fragmented and ill-defined, with poorly developed team working. The promised Primary Care teams began to be established towards the end of my fieldwork. Ideally, and in accordance with policy, the immense variability in health and deprivation at a local level between areas would in turn demand variability in resources and services. This would be determined through local needs assessment which could also provide a focus for community involvement (Department of Health, 2001). During the course of my field work no such needs assessment had been conducted or planned by the state agency responsible for health.

I draw comparison between the illustration of Primary Care which I found on the ground in north inner city Dublin figure 15 with what was proposed in the Primary Care strategy figure 16 and what the review team found in the ten implementation pilot projects around the country figure 8. This illustrates the difference between the aimed for system and the actual lack of system

Figure 15: Primary Care: a non-system of community services

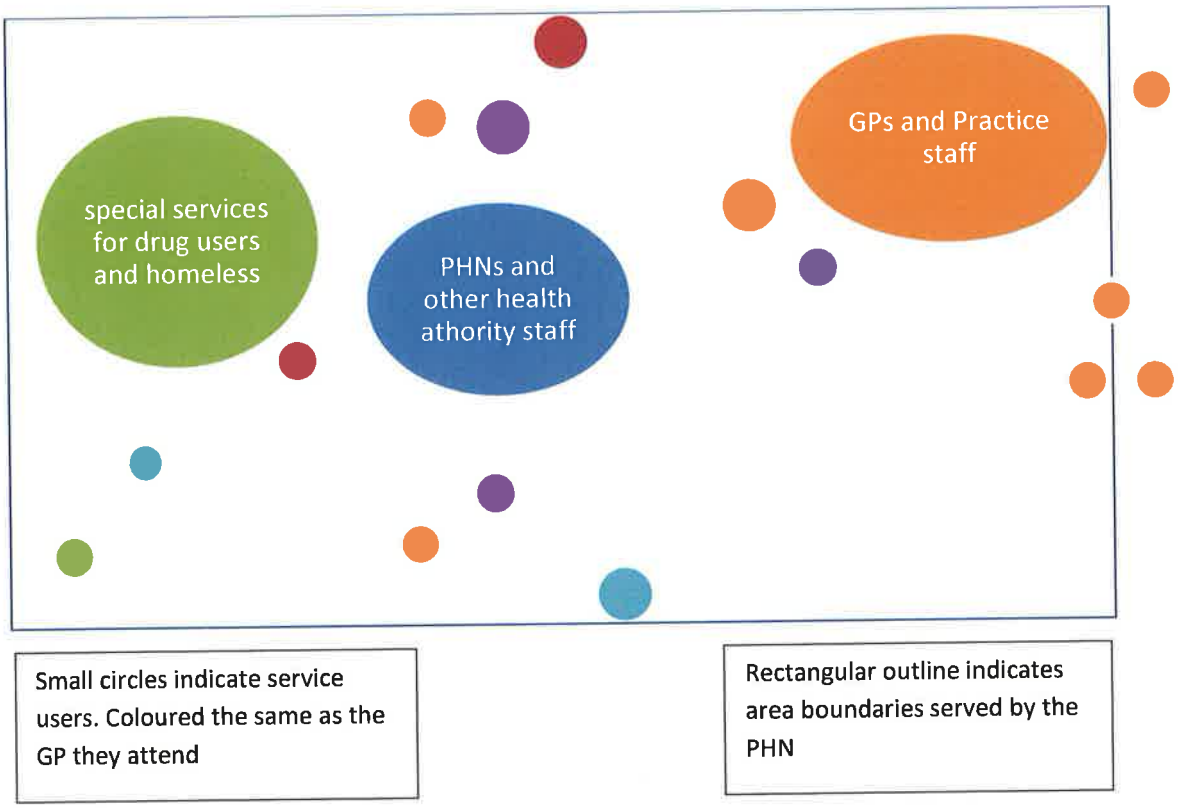
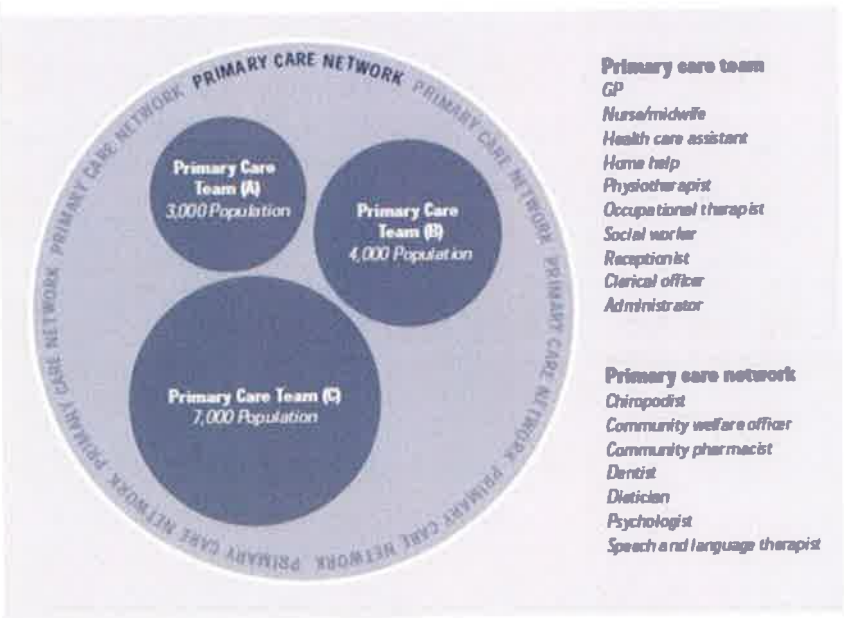


Figure 16: Primary Care Teams and networks as envisioned by the Primary Care Strategy



Chapter 7 Community Participation in Practice

"Liberation is a praxis: the action and reflection of men and women upon their world in order to transform it." (Freire 1970)

This section presents findings from my exploration of the community sector in north inner city Dublin. It is divided into four parts: the first describes the organisation and activities of the sector, the second identifies and describes spaces for participation, the third explores community involvement in health issues and the fourth discusses looks at decision making dynamic and finally findings are discussed under space, decisions and definition.

It's 2.30pm, a bright spring day in February (2006). As I approach Leinster[13] House on Kildare Street I hear drums beating and the crowd chanting. The protest is confined to Molesworth Street directly opposite Leinster House. There are about 1000 people present. The protest appears well organised. Barriers and a few Gardaí line the street which contains the protesters. People are waving banners, holding tapestries which commemorate those who have died as a result of drug use. I recognise many of the people present. I take my recorder out of my bag and begin interviewing. I ask a cross section of demonstrators why they are marching and what they hope to achieve. They tell me they are here to support the community representative to the National Drugs Strategy Team (NDST), FMcC who had resigned his position as a result of a loss of confidence in the government's commitment to the National Drugs Strategy (Government of Ireland 2001). Opinions vary on whether the protest will influence any change. One

Community protest outside Leinster House (2006)

Seanie Lamb and Tom Redmond at protest

[13] The building is the meeting place of Dáil Éireann and Seanad Éireann, the two houses of the Oireachtas and as such the term 'Leinster House' is the symbol of Irish political activities.

participant from a drug training and rehabilitation project explains why he is here.
"We're making our voice heard because rehabilitation and drugs were supposed to be a major plank in the Government's policy on drug strategy, and now, and over the years, they're clawing back, they're clawing back, and they're not listening to the community"

A drugs service user is concerned about reduced funding.

"There's a terrible lot of people in recovery, in drug recovery and all, me as well, few months taken off me life... there's a lot of people there. If you don't get the money it's not only the staff that they let go, the participants will be let go as well so it'll mean a lot of people back on the streets, a lot of people probably back on drugs, homeless, a lot of that.. for the sake of money!"

After more chanting and drum beating some supporting politicians form different parties stand on the steps of Buswell's hotel, presumably so that their support is seen by the crowd. FMcC stands on the steps and addresses the crowd. Thanking the projects and politicians he highlights the need to continue the successes achieved over the years and the need for the partnership approach;

"Everybody knows that there is, in reality, a very serious drugs problem. We also know that when you've got the communities and the voluntary sector together... when you've got them working with the statutory groups together, we produce many of the projects that we're seeing here. We produce projects that save people's lives."

[shouts of "hear, hear" & cheering]

".....more importantly that we show that if you have a genuine partnership process, if it is genuine and if you do put the sorts of resources required into addressing this problem, you can make significant progress. And we did make significant progress."

The speech goes on for about 15 minutes and is well received. The protest is deemed successful by all involved.

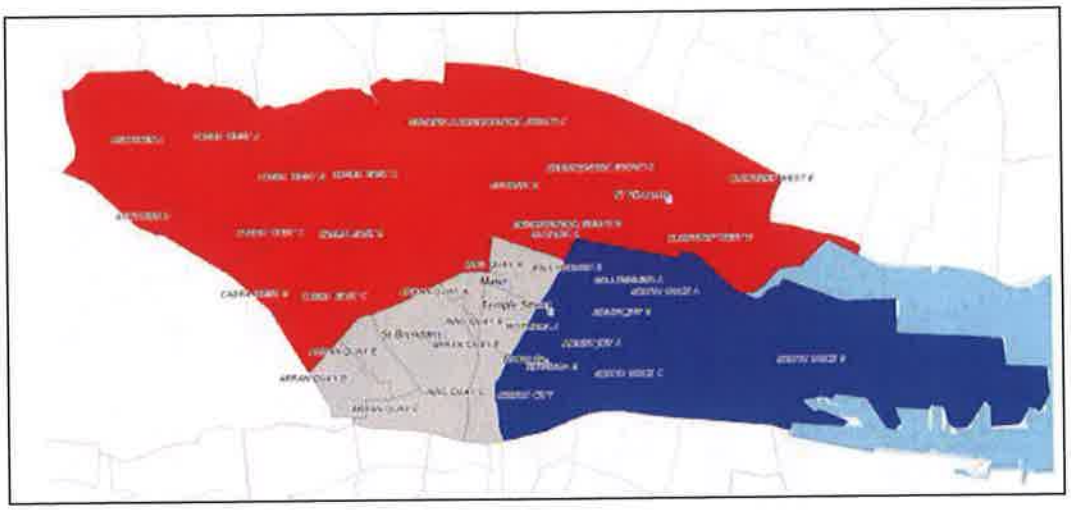
The scenario above sees the community and voluntary sector drugs groups and projects from all over Dublin City, come together to voice their objection to what they perceive as a lack of commitment to the national drugs strategy partnership process. The partnership process evolved gradually out of a response to wide scale heroin addiction and consequent ill health in Dublin's deprived inner city in the eighties and nineties. The national drug strategy eventually focused on supply reduction, prevention and treatment (Government of Ireland 2001). Treatment relied largely on the medical model for opiate use which favoured methadone maintenance therapy (MMT). This treatment strategy relied heavily on Primary Care for service delivery (Department of Health and Children 1998). Community groups had come together to challenge the state about their commitment to the partnership process.

As far as community sector participants were concerned, all the relevant stakeholders were present at the protest; politicians, community groups, residents, drug users. In conversations with community sector participants later it appeared that the absence of Primary Care professionals seemed only relevant to me. They were not expected. Though addiction treatment was a major part of the National Drugs Strategy (Department of Health and Children and HSE 2008;Government of Ireland 2001), and many of the projects and groups present at the protest were funded by or through the health authority, the health sector were not seen as part of the community sector. Conversely, in spite of much funding from the health authority, the community sector was certainly not part of the health sector.

Organisation and Activities

In exploring 'community' on the ground in the north inner city I engaged with the community and voluntary groups as represented by the two network organisations in the east and the west of the inner city. My main focus was the community structure in the north east of the city which was the most deprived. This was the catchment of the Inner City Organisations Network (ICON), the Chair of which sat on my advisory committee for the first year of the research. The west of the inner city was covered by a newer community organisational network North West Inner City Area Network (NWICN). Both network organisations' catchments are represented in figure 17 below.

Figure 17 The NICP EDs (in colour) showing community networks' catchment areas



ICON area: blue NWICN area: grey *Created by Health Atlas, HSE 2006*

Both networks are umbrella organisations whose aim is to link up voluntary and community groups operating in the north inner city Dublin as well as individuals working and living in the area[14]. They co-ordinate and disseminate information, operate as forums for debate and local policy making, and provide means for lobbying on issues as they arise within the community. The networks aim to promote collaborative 'partnership' between state, non-state, business and community groups in the area (DICPet al. 2004).

The chairman of ICON, (SL) pointed out that there was not simply one community in the north inner city but rather that there were several individual communities. Indeed, for some, views of community extended no further than one's own street or block of flats.

> *"the Stonybatter area does not identify with O'Devany for example. As for the republic of Sheriff Street, they identify with no one" (Interview with SL)*

The reference to the 'Republic' above indicating that people living on this street (Sheriff Street) say themselves as autonomous and did not want to lose their independence by joining with other groups.

[14] The networks differ slightly in that while full membership in NWICN was open to community and voluntary groups only with individuals registered as friends, ICON allowed membership to both groups and individuals

The numerous groups which came under the umbrella organisations included community projects, local tenant's groups, as well as individuals working and living in the area (see appendix V). The networks were established to strengthen communities' voice and influence over factors affecting them, such as drugs, education, housing, intercultural issues and the impact of urban development (NWICN 2004). SL believes the development of the networks strengthened community voice:

> *"Previously there were loads of community organisations, but nobody could speak on behalf of them all. I now have a mandate here from, not from the people who live here but you know those who work with them, and those who are on the management committees, and they almost all have local people on the management committees" (Interview with SL)*

A long tradition of communities responding

There is a long history of community development in the north east inner city. Over the past few decades, many partnerships and community platforms have been established. The local community have come together on issues such as drugs, housing, and the collapse of local employment in the docklands. From experiencing these crises people developed skills that were later used to promote personal and community development. community development principles are used by a number of organisations working in the local community e.g., the Neighbourhood Youth Projects, Lourdes Youth and Community Services, and community development projects (Weafer and Weafer 2004).

In the 1970s unemployment was the determining factor for low levels of income. Much of the employment for people in the north inner city had been in the docklands and related companies. With the introduction of the use of containers in the transportation of ships' cargo there was a drastic reduction of jobs. Traditional industry such as textiles suffered from foreign competition and factories were forced to close. Other companies relocated to cheaper land on the periphery of the city. In parallel, the housing policy aimed to de-tenant the inner city moved large numbers of families out of the area. Construction of large office developments required a different skills base than that available locally (Connolly 1997;Kelleher and Whelan 1992b).

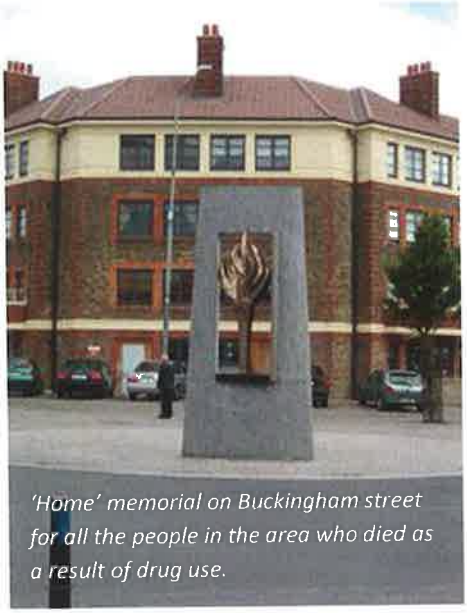
In response to the deterioration of the north inner city, local community residents formed the North Centre City Community Action Project (NCCCAP). It composed of two delegates from each of twelve tenants association already existing in the area. Early objectives were to oppose the depopulation of the local area. The NCCCAP created the space for residents to express their concerns about the plans and to have a voice to object to them (Kelleher and Whelan 1992b). The then secretary of the group Tony Gregory was elected to the City Council and subsequently to Dáil Eireann. In the now famous 'Gregory Deal' the balance of power between the two political parties came down to just one seat. Tony Gregory was in a position to offer support to the party which would do most for the north inner city. The Fianna Fáil government gained power as a result and the housing development they instigated in the north inner city commenced. De-tenanting was stopped, SL explained:

> *"Well the first thing was the plan that the Corporation had to depopulate the area went straight into the bin. Now a lot of that had been done already, the old houses on Gardiner Street and Sumerhill were already knocked down. Sean MacDermott Street was about to be knocked down at the same time. So a lot of families had moved out of the area, but basically what he[Tony Gregory] got was sixty million off Charlie Haughey, which Tony gave to Dublin Corporation as, it was at the time, to build housing in the inner city. So that kind of snookered their plan if you like." (Interview with SL)*

The influence of the north inner city community affecting change through the Gregory /Haughey deal has been well recognised. According to some, the Urban Renewal Schemes first introduced in 1985 were a consequence of this deal (Connolly 1997). NCCCAP with an articulate leadership and strong local base succeeded in publicising issues related to urban renewal. The Dublin Corporation (now Dublin City Council) was not in the habit of consulting with local groups at the time. The expert's task was to plan without reference to local demands. This made for a hostile relationship with community. Campaigns led by the NCCCAP led to important changes regarding urban renewal and the Corporations plans were modified as a result (Kelleher and Whelan 1992b).

Another early success of the NCCCAP paved the way for local groups to be funded by government to provide services. It gained control of the summer projects which were funded by Dublin Corporation and administered by the Catholic Youth Council. Local communities

wanted control of the grant and for jobs to be filled locally. It received core funding from Combat Poverty and for a further year from the Department of Social Welfare. After which it was funded through administering community based training and employment schemes. Today the NCCCAP focuses on training and empowerment of trainees.



'Home' memorial on Buckingham street for all the people in the area who died as a result of drug use.

The devastation the north inner city communities experienced as a result of what is now known as the 'heroin epidemic' cannot be underestimated. In the early nineties the effects of the first wave of the heroin crisis were beginning to be seen. Many young adults were reportedly dying as a result of drug overdoses, drug related suicide and aids related illnesses. Drug related crime was at an all-time high and some local authority flat complexes were used as open markets for all kinds of drugs (Lyder 2005;Murphy-Lawless 2002). People were injecting openly and discarding injecting equipment in school yards and children's playgrounds. Neighbourhood committees were formed and drug dealers, often addicts themselves, were sometimes forcibly evicted from their homes (Lyder, 2005). Treatment for addicts was virtually non- existent and GPs were often reluctant to prescribe methadone. One local woman had three children who died as a result of heroin use described the difficulties in getting treatment at the time;

> *"When he came home from hospital, I'd an awful job getting a doctor for him [lists five local GP who would not take him, stating their lists were full]... At that time it was, people were afraid".*

> *"I used to cry, I did cry, but ah, the AIDS Counsellor, she come down and I was telling her and she says don't worry (name) she says, I'll have a doctor for you, she says. So Dr. (name) come then the week after. God twice a day he came out to him, morning and evening, he was marvellous. He gave him a prescription, do you know where I had to go for to buy it [methadone on black market] I said to him, Rialto. I got it that day, two days after it was gone. Dr.(name) comes, says I doctor I have no methadone. But says he Mrs. (name) I gave you a prescription. I gave it to him says I. Ah sweet God*

says he, come out, he brought me out into the kitchen. Ah says he, look says he, there's a prescription get two bottles and give him what he wants he says because it won't do him any harm he says. Because you know he says, he hasn't long to live. Of course I knew it, I was told it. Now, I went to get two bottles and there used to be a Policeman at the door, waiting on me, because young fellows out there would snap it out of your hand." (Interview with local woman)

In the early nineties north inner city communities were among thousands of people who marched on the Dáil demanding a comprehensive response from government. Community leaders insisted that the community be involved in any policy making. In 1995, people in the most disadvantaged communities across Dublin city were trying to deal with the devastating impact of the drug crisis on their local areas. ICON took the initiative of inviting groups to come together to a meeting in Liberty Hall to launch a joint campaign on behalf of all the communities affected. This was the beginning of the Citywide Drugs Crisis Campaign(UISCE 2003). There was a sense of anger and alienation in many of the areas affected. In a climate of political agitation on the ground at community level, and public outcry after the murder of crime correspondent veronica Guerin, the first ministerial report in 1996 recommended the establishment of the Local Drugs Task Forces (LDTF). The link between severe poverty and opiate injection had been identified at an early stage of Dublin's widespread use of heroin. However, it was not until 1996 that a Ministerial Task Force publicly accepted the centrality of this relationship(Saris 2008). The LDTF was established allowing community involvement in the response to the drug crisis in the area. The LDTF members included community delegates, drug user representative (UISCE), elected representatives and statutory bodies. ICON nominated and supported community representatives on the drug tasks force. Community members became involved as service providers establishing drug projects, worked in drugs projects, and as representatives on forums. They were involved in designing and implementing the local response to the drugs crisis under the themes: supply and control, treatment and rehabilitation.

Strength in one voice

On the East of the city the development of the 27 acre site known as the Docklands highlighted the need for a stronger community voice and representation. The north inner city community groups had identified the social and community need for the area to be developed in the

interests of the local people. However this did not happen and a Financial Services Centre was developed under the Customs House Docks Development Authority (CHCA) primarily as a business district. While the Authority showed some willingness for dialogue with the groups from the surrounding area they never allowed them any real influence, arguing that these local groups did not represent the community. In fact it was not until the Labour Government came into power that the Dublin Docklands Authority was established. The lack of representation argument used by the CHCA stimulated community groups to respond by coming together as a network. In the mid-nineties the Dublin Docklands Development Authority, were given the remit for the social and economic regeneration of the Docklands area. The effect of this policy change was significant with the enshrining into legislation the right for community groups to nominate people onto a council which would act as an advisory council to the Executive Board. With the establishment of ICON there was a mechanism which provided for community representation. This made up for the failings of poor participation in the normal macro-democratic process of people exercising their vote in the traditional way.

Similarly in the North West during the 1990s, a major building development (Dublin Corporation HARP Project), resulted in major physical environmental change. Although surrounded by a multimillion pound development, people felt very much 'on the periphery' (Rourke and Kenny 1999). Local activists and community workers involved with training groups, workers coops, tenants groups as well as statutory and voluntary groups saw the benefit of merging into a cohesive unit in order to increase capacity and influence

Coming together to identify needs

Concepts integral to definitions of community development are that people work together to identify their own needs and create change so that they may exert more influence in the decisions which affect how their lives are (Motherway 2006b).The organised networks in the north inner city are examples of how this process worked.

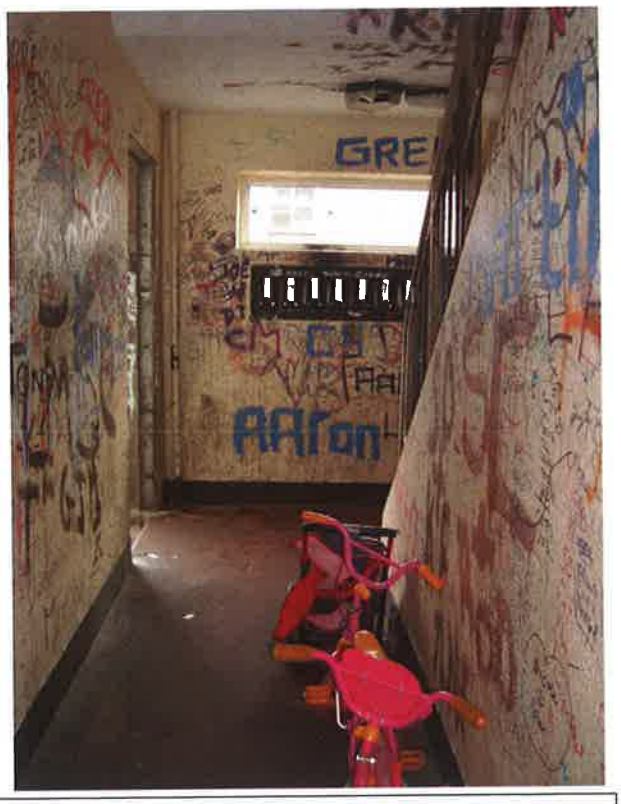
Looking at community action over the last three decades presents a picture of communities coming together in response to problems imposed from the outside. The need for training courses and workshops arose from the high unemployment caused by de-industrialisation. The tenants groups came together in response to problems with housing; the demolition of old housing stock and the inadequacy of maintenance. Drug projects and the community policing

forum developed as a result of the "heroin epidemic". Involvement on the Dockland's Development Board and work with tenants and residents came as a result of the physical developments being imposed without local consultation, on the city. The community sector evolved through response to external stimuli and that response endeavoured to protect and represent the residents and fight back when necessary.

The activities' of the community based organisations operating in the north inner city were reflective of their interpretation of community needs. Priority areas are identified and action plans are drawn up through consultation with member groups. Working groups are established according to priority areas. Consultation has taken the shape of annual general meetings, facilitated workshops, and research including interviews and focus group discussions (ICON 2002;ICON 2006;ICON 2007a;NWICN 2003;NWICN 2004;NWICN 2006b). Each network also employs a community participation worker to support and facilitate local people's involvement in member groups.

Action plans for groups in both areas are determined at major two day workshops every couple of years. These planning conferences achieve participation from hundreds of individuals from community groups, services and statutory bodies. Areas for action over the period of this study included; education, intercultural activities, drugs, employment, family and youth, childcare, empowering youth and involvement in local area development plans, among others. The drugs issue has been a major and recurring focus, encompassing policing, treatment and rehabilitation. Health has only been introduced on the agenda in both networks strategies in 2006. It is mentioned peripherally and not as a main theme like education, employment or drugs. In the west of the city it was introduced through needs for people with disability and older persons. The NWICN had also established a working group to ensure community involvement in a major development on the Grangegorman site. This was to include a university campus and health care facilities. In the east of the city health is beginning to emerge as an issue to become involved in. The establishment of a health forum was planned by ICON (ICON 2006;NWICN 2006a;NWICN 2006b). The photographs below capture one of the networks member projects: O' Devany Gardens community development Project. The photographs are intended to depict a theme I found in many of the groups and projects I visited in the community: local people meeting local needs in deprived environments.

O'Devany Gardens community development Project



This converted flat in O'Devany Gardens Local Authority flat complex on the west of the city. The development centre offering a wide range of courses - IT skills, cookery, literacy, Leaving Certificate; small crèche for users taking part in the courses.

Spaces for Participation

The recent history of the north inner city has shown that residents of this area are not averse to organising themselves to challenge drug dealers or statutory bodies. However, participation in the electoral process is limited to a relatively few individuals. This tends to be countered through participation through local representation on state bodies (e.g., Drugs Task Force, Dublin City Council) and on Boards of independent development companies (e.g., Dublin Docklands) (Weafer and Weafer 2004).

ICON was committed to pursuing the partnership approach between statutory and non-statutory sectors as well as actively encouraging the participation of local tenants and residents in different spaces for participation. This partnership approach opened new spaces for community participation. This partnership approach had not always been the way of

working but much was achieved through it, according to the ICON Chairman at the opening speech of the fifth Icon conference:

> *At that stage we had been continually in conflict with the state without success so we decided to give the new idea [partnership] our best effort.*

He goes on to say that this way of working had been "remarkably successful" listing the successes as:

> *The major reduction in unemployment, the housing refurbishment, the environmental improvements, treatment and rehabilitation programmes for drug users, the Community Policing Forum, after schools projects, the money advice service, crèche facilities the integrated Services Project, the Docklands Development Authority, family support and many other initiatives that have been achieved through the partnership model of working (ICON2002).*

Within the north east inner city there were many opportunities for community participation through the ICON structure. ICON had links with the Dublin Inner City Partnership, Dublin City Council, FAS, City of Dublin Youth Services Board, the Probation and Welfare Service, the Department of Social, Community and Family Affairs, the VEC, the Department of Education and Science, the Drugs Task Force, the North Eastern Health Board[15] and the Gardaí.

There were a plethora of government initiatives focusing on areas of deprivation for development. Through a complex funding and governance structure government supports local community development. There were also many spaces for participation in the form of area based partnerships. Pobal (formerly ADM)[16], an intermediary not for profit company was established by the Irish Government in agreement with the European Commission to promote social inclusion, reconciliation and equality, and to counter disadvantage through local social and economic development. ADM had responsibility for the Local Development Social

[15] This was prior to the abolition of the boards and the establishment of the HSE in 2005

[16] Established in 1992 as Area Development Management, ADM changed its name to Pobal in 2005. Pobal is an intermediary that works on behalf of Government to support communities and local agencies toward achieving social inclusion, reconciliation and equality. Pobal is a not-for-profit company with charitable status that manages programmes on behalf of the Irish Government and the EU

Inclusion Programme (LDSIP). This Programme was managed locally by Partnership companies(ADM 2005). The Partnership Company, through which NWICN and ICON received core funding and support, was the Dublin Inner City Partnership (DICP).

The Dublin Inner City Partnership (DICP) aimed to promote social inclusion and address long term unemployment. The board is drawn from the private, community, trade union and statutory sectors and elected representatives. Community directors are nominated by the four community networks operating in the north and south inner city(DICP 2001). The DICP approach provides a strategic framework for sustainable community regeneration with an emphasis on partnership and community-based responses (DICP, Local Networks, LDTF, and Community Development Projects 2004).

The government's RAPID[17] initiative provided a space locally for local statutory, non-statutory agencies and community representatives to meet regularly to identify and respond to local needs(ADM 2001). An early needs analysis undertaken by ICON and RAPID identified among other things the need for a multipurpose one stop shop for community services and facilities including a crèche, after schools programme and a Primary Health Care Programme, which never transpired (ICON/RAPID 2001).

Up until 2005 the north east inner city was situated within the Northern Area Health Board area. As previously stated the Board allowed for elected representation participation (O'Hara 1998). The north east inner city came under Community Care Area (CCA) 7 and the north east came under CCA 8. In 2005 with the abolition of the Board CCA were renamed Local Health Offices (LHO), Dublin North Central LHO and Dublin North West LHO respectively. There were no area based partnership spaces specifically on health /health services in which local community representatives could be involved. The health authority supported the community and voluntary sector through significant funding [18] and the LDTF coordinator was a HSE employee.

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[17] The term RAPID denotes Revitalising Areas by Planning, Investment and Development. It is a national programme aimed at improving the quality of life and the opportunity available to residents of the most disadvantaged communities in Irish cities and towns.

[18] In relation to support provided to the community and voluntary sector, the Health Boards provide grants under Section 26 (Health Act 1970), Section 65 (Health Act 1953), and Section 10 (Childcare Act

The Dublin City Council (DCC) was responsible for the social, economic and physical rejuvenation of the north east inner city area, working in partnership with all of the voluntary and statutory bodies and the local community. Seeing the commonality between the goals of this state body and the local community the need for engagement was recognised and a protocol was established (DICP and DCC 2004).

It provides a framework and mechanisms for engagement which would be facilitated through area network organisations. It specifies joint fora to maintain communications, for understanding, and resolving issues. It is signed by the City Manager on behalf of the DCC and by the Director of the DICP on behalf of the 'Dublin Inner City Local and community development sector'(DICP and DCC 2004).

The North Inner City Drugs Task Force (NICDTF) was a partnership between the statutory, voluntary and community sectors. Local Drugs Taskforces (LDTFs) were established in the areas experiencing the worst levels of opiate misuse. Dublin North Inner City (NIC) was one such area. The drugs task forces came under the governance structure of the National Drugs Strategy Team (NDST) which is also a partnership of state community and voluntary sector and some medical personnel. Part of the NDSTs role was to account to the government department with responsibility for drugs. An inter- departmental group approved the drug task force plans and monitored and evaluated their outcomes with the NDST. This structure implements the national drugs strategy, which resulted from a broad consultation with all stakeholders.

The LDTF coordinators were health authority employees. Their membership includes all the relevant state agencies including Police, Education, City Council, Health and community and voluntary representation as well as drugs service user representation through UISCE[19]. The

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1991) to bodies that provide a service similar or ancillary to a service that the Health Board may provide. Over €100 million is distributed under this scheme annually and it is the single largest source of state funding to the voluntary sector. Weafer & Weafer 2004

[19] The Union for Improved Services Communication and Education (UISCE) is a drug users forum based in the North Inner City. UISCE work to ensure that those in need of services have their voice heard by

north inner city Dublin LDTF oversees approximately 36 community drugs projects. After a period of funding through the LDTF and satisfactory evaluation, projects are generally 'mainstreamed', which means that long term funding is guaranteed, on an annual basis directly from state bodies A subcommittee with delegates from community members and drug service users engage on an on-going basis with the drug treatment centre.

Cornwall (2002) describes these 'invited' spaces for participation as 'regularised relationships' which serve as an interface between people and authorities of various kinds, generally those of the state. In these spaces citizens become part of the machinery of governance. They are conferred with statutory powers to allocate resources and exist through statutory provision. Cornwall sees this type of partnerships as having limited prospects on official policy but with opportunities for members to shape de facto policy in practice through relationships with statutory workers which continue outside these spaces.

This in fact occurred in the case of the RAPID partnership, from which the community delegates had suspended participation. Relationships with health officials allowed other opportunities. Gaventa (2006)reminds us that those who create the spaces for participation and 'invite' involvement from others including community are more likely to have power within it, but also those who have power in one, may not have so much in another. Some of these spaces though falling under the 'invited' category as established by government did in fact leverage considerable influence. The Drug Task force for example facilitated the creation of new projects and initiatives (through administering funding for the State) which broadened further participation of those otherwise excluded.

The rich history of and experience of local activism among groups and individuals in the north inner city as well as the role of the network organisations and the DICP undoubtedly countered risks of the reproduction of power differentials which Cornwall and colleagues say are always present in invited spaces (Gaventa 2006). The network organisations provided what Cornwall says are 'associational spaces' outside the formal intermediary intuitions of governments. These spaces though created with government funds offered relatively independent sites in

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policy-makers and practitioners. UISCE represent the voice of drug users on many relevant fora, and engage in a number of key activities http://www.nicdtf.ie/PROJECTS/PROJECTS/UISCE.html

which those who participate in invited spaces may be active gain knowledge experience and legitimacy.

Community methods for mobilizing power

Enhancing community involvement requires more than providing spaces for participation. Being included in the policy arena does not always mean one will be able or permitted to influence decision making. Cornwall says these they are infused with existing relations of power interactions within them and may come to reproduce rather than challenge hierarchies and inequalities (Cornwall 2002). Participation of community delegates in different spaces was undoubtedly enhanced by support structures such as networks by providing information and training as well as (and suggested by Garventa, 2004) by linking different strategies across spaces, levels and forms. Cornwall asks of 'invited' spaces, " what tactics do those with little voice and power use to gain access resources or influence?"(Cornwall 2002). Some tactics used to mobilise power by community are detailed below.

Supporting community delegates: The network organisations discussed in this chapter offer practical support to community delegates on committees. They are supported by the network staff and have the opportunity for training, development and information sharing. The networks view empowerment as an integral part of participation.

A multi-level structure of participation: FMC (community representative on the NDST) identified the multi-level structure with community representation at each level as important in strengthening community influence. From successive interviews I summarised the lessons from the successful community participation in national drugs strategy (Figure 18). As the National community representative he maintained continuous engagement with Local community representatives, sharing information on national developments and getting their views and inputs to feed back at the National level. This meant those local community representatives were often apprised of national developments before their statutory counterparts which was empowering. Also the national rep was seen to have a local constituency and in depth knowledge of priorities.

Figure 18 Lessons for community participation in the national drugs strategy

Lesson drawn from interviews with FMC on successful community participation

1. Establishment of agreed structures for on-going involvement (NDST Local and Regional Drugs Task Forces)
2. Clear roles and responsibilities for each structure
3. A budget and decision making power
4. A clear plan with buy in from all stakeholders
5. Externally monitored and evaluated review
6. Broad consultation prior to each strategy
7. Power to design local strategies
8. Never sit back, always challenge.
9. Demonstrated political commitment
10. Active protest including non-participation is always an option

Non participation: The RAPID initiative which had stimulated a huge amount of expectation that extra resources would be made available to the area led to serious disappointment when expected additional funding did not materialise. As a result community delegates for the north inner city stopped attending RAPID AIT (Area Implementation Team) meetings for a period in 2004 stating they were 'suspending participation' from the initiative. One community representative explained;

> *We were so annoyed with the timeframe you know. Really, really annoyed we were. By that stage there wasn't an awful lot we could do about it. So, every month then we'd meet, you know ,the AIT meet every month, and this was supposed to be.. RAPID was supposed to be a fast track way, of getting money down, but sure even for the State agencies, there was nothing coming down, from the proposals they put in, there*

was nothing coming down from the different Departments, and I think it was about a year and a half this went on, and we couldn't see anything happening on the ground, any changes, ye know, so the community delegates suspended from the AIT (Interview community delegate 2004)

Protest: Though much had been achieved through partnership on the drugs issue in 2006 the community sector lost confidence in the government commitment to the Drugs Strategy. There was a lack of funding and a perceived down grading of the issue in political terms. The 'drugs' portfolio was demoted to a junior minister who also had the 'housing' portfolio. There were delays in replacing state agency representatives to the National Drug Strategy Team. After presenting concerns to government without adequate response the community representative to the NDST resigned from the partnership and the sector staged a demonstration (described in the opening scene, chapter 1).

After the general election, a senior minister was appointed, but it was still effectively a half time post. Funding was not guaranteed for Local tasks forces on the basis as it had been previously been. Instead projects would need to justify their continued need through reapplications to an 'emerging needs' fund. FMC was replaced by another community representative on the NDST.

Political influence: Community groups use the political process successfully to influence change. Community representatives are experienced community leaders with considerable political savvy and abilities (Weafer and Weafer 2004). This and the physical proximity of the community network offices, community projects, the local drugs task force and the city council offices next to one another in the heart of the north east inner city also facilitated dialogue.

This history and description of activities and spaces for participation sees community respond to issues which impacted the local people. Involvement in formal health services was less conspicuous. I looked for specific cases studies where communities did become involved in a health agenda.

Community Involvement in health

As there was no dedicated space for participation in a health agenda I looked for examples where communities were involved in health issues. The first case study sees community involvement result in small changes to one of the health centres in the area. This space is what Cornwall and colleagues describe as an 'invited' space. In the second the community sector supported by the health authority community development worker (CDW) conducted a health assessment in a community undergoing regeneration. This was a 'claimed / created' space and was transient in nature (Cornwall 2002). The 'third' space was also a created space in which ICON challenged sanctions being used at the local drug treatment centre.

Case Study 1: Health Centre Design

The Area Implementation team for the RAPID initiative was a partnership involving statutory and non-statutory agencies as well as community delegates. The community delegates were put forward and supported by ICON. Health Board representatives were the General Manager and Social Inclusion manager for Community Care area 7 which contained the north east inner city among other sizable areas.

The General Manager invited the community delegates to become involved in assessing the suitability of one of the health centre's physical infrastructure (North Strand Health Centre). One issue emerging was privacy for people as they waited to be seen in the mental health clinic. Community delegates also identified the lack of signage as a problem. The community representatives with the General Manager, decided to hold an 'open information day' in the clinic and produce an information leaflet of services.

Though the 'open day' was not particularly well attended by the local residents the event was deemed a success. The services within the clinic benefited as those providing one service became aware of other services within the clinic that they were not previously aware of. Necessary changes were identified and made. Staff working in the clinic indicated to community representatives that they had little or no influence to make changes themselves and were pleased with the supportive involvement of the community. The community delegate described the outcome:

'They have actually partitioned some of the waiting area, not on the corridor but in where the other services were to accommodate the clients, and we got speaking to the head of the Community Welfare Officers, and they turned around and said to us, 'we want to thank you' because the staff, were actually working in little cubby holes, and because of our involvement we made the change to their working environment but also to the clients using the centre.' (Interview community delegate)

The community delegate's experience of this engagement with the health authority was positive. Crucially, they felt that, the fact the General Manager they were dealing with, was keen to have them involved and eager to push their recommendations through.

Case study 2: Blackhall community forum health assessment

The Blackhall community forum was established in response to the planned regeneration in the Blackhall area (a collection of local authority houses and flats consisting of 166 units in the north west inner city). The forum committee comprised a Health Board community development worker, a Dublin city council worker, a local community development project worker and local residents. The forum was established initially to combat the disintegration of the local community as a result of the change in population (old families moved out of the area when it fell into decay and new ones moved in when it began to be regenerated). The forum was instrumental in developing a range of activities and services including a crèche, an after schools project, a youth service, a women's group and resident's group.

Health issues began to emerge as an issue of concern during the regeneration. The community forum was successful in securing funding for the assessment of health needs. A researcher was employed who supported four local women to administer the questionnaire. The survey was undertaken in 2002 and achieved a response rate of 80%.

A summary of findings from the Heath Assessment

The level of satisfaction with own / family's health status was high and comparable to national studies. However the use of secondary services and proportions on prescription medication was higher than national comparisons (49% had made hospital visits over the previous year and 52% were currently taking prescription medications). Eighty three per cent of respondents had visited a GP in the previous year which is higher than the national level (64%) and only 12% had visited the health centre. Fifty present had difficulties accessing the GP service due to difficulty in getting appointments and long waiting times. Fifty three per cent were satisfied with GP services which is considerably lower than the national rate at 86%. The majority of the respondents were only aware of GPs and the Health Centres as health services in the community and complained about the lack of information people had about existing services. Most people (68%) felt their needs were not considered in health service planning and 60% were dissatisfied with health services available. Emotional problems and debt problems were highlighted. Stress was higher than expected and environmental issues caused most concern (building work, infestation, noise pollution, traffic, and crime). (Lansdowne 2007;Unique Perspectives 2005)

Recommendations included the need for access to services locally e.g. dental care, speech and language services, and services to deal with the high levels of stress and anxiety identified in the survey. The redevelopment of the resource centre was seen as a priority, saying it could be used for a range of health related activities and to assist in information strategies.

Recommendations included; the refurbishment of the local resource centre; a health promotion strategy with the newly formed HSE; a range of education and training initiatives;, the development of a range of activities for young people, and improved community involvement through a community development approach (Unique Perspectives 2005). Recommendations on information dissemination resulted in a presentation to the North Inner City in Primary Care.

Formal engagement between the forum and NICP did not occur because of the closure of that space (see chapter 8). Recommendations to improve Primary Care services were over taken by developments in another space. The planned development of Primary Care services as part of the Grangegorman Development would serve the Blackhall community and provided a tangible

opportunity for community involvement which the exiting and fragmented services did not. The NWICN's priority was therefor to engage in the new space about Primary Care development.

Blackhall before during and after regeneration (photos Fidelma Bonass (CDW, CCA6)

Case study 3: Defending drug service users right to treatment

A specific example of community involvement with the drug treatment clinic saw community members challenge clinical decision making.

Through clinic clients attending one of the drug projects, ICON became aware that people attending the clinic were having methadone reduced in response to 'behavioural' issues. SL did not feel that 'medicine' for addiction should be used to control behaviour;

> *Effectively what that meant was that the clinic operated a system of behaviour control eh by using medication, in other words reducing your medication for bad behaviour. Or even more worrying still where there wasn't serious bad behaviour but simple things like lateness been late for your appointments you were docked (Interview with SL)*

ICON took the view that if the 'medicine' was needed on medical grounds then it could not be reduced simply because the clinic judged behaviour as 'bad'. They contacted one of the local politicians who sat on the Northern Health Board at the time who told them who to contact in the Health Board. ICON threatened to take the issue to the Dáil and have a city wide campaign if the practice did not stop.

A meeting was called with the clinical team at the clinic. The assistant manager of the NAHB was present as was 'significant' community representation as well as UISCE representing drug service users.

The practice of medically sanctioning clients was stopped and protocols were devised jointly to manage situations where behaviour was affecting health and safety.

While one third of those receiving methadone do so in GPs private practices there was no mechanism for community involvement. It was the view of the ICON Chair that if a complaint came to them about a GP engaging in this practice he would advise the patient to change his GP. If the practice was widespread they would take it up with whoever they had to "the Health Board, the GP or the IMO". However there were no mechanisms to speak to GPs as a collective or mechanisms to assess their practice.

The three case studies show community involvement in specific health issues by way of response rather than plan. Through participation in different spaces the community were able to access decision makers in the health authority. The position of the health authority community development worker (CDW) created an on-going interface between the community and the health authority. However no dialogue was stimulated between the community and professional Primary Care services. In the case of involvement in the drug treatment clinic the connections with the political process was used to bear influence. This was the only case where community members came in contact with a clinical team. The first case study involved quite senior health authority managers and community delegates in low level decision making, resulting in minor changes to the health centre.

Both the identification of spaces for participation and the exploration of cases of community involvement in health highlights a lack of a space for participation at a health service planning or management level. The exploration of spaces for participation resulted in health authority staff involvement in various partnerships. GP private practices (the most utilised element of professional Primary Care (Lansdowne 2007) were not represented in any of the partnership spaces nor in community fora. There was no history of GP involvement in community work and no expectation for their involvement. A resident and community participation worker in one of the networks considered the lack of GP involvement;

I think people see that they don't live in the area to start off with. You know they come into their surgeries and they're gone again. They're like a service provider but without much real connection to the community .... I mean there is a connection, say with the Health Board, whether it's only, you know, the baby nurse will come out from the Health Board, if it's a need, the welfare worker, that's the Health Board, so there's people going for something, you know there's some give and take you know, but, there isn't any doctors in the Health Boards so, you know what I mean. They used to be. I remember when I was a kid. You went to the dispensaries for your needles and you went there to see the doctor, you know that's how you see the doctor. You didn't go to a private surgery; you went to the clinic, the dispensary. So that's gone, so I don't see that people connect the doctor with the Health Board.(Interview with local worker)

Establishing a space for Health participation

Health or health services had not, up until 2006 been specially included in the network organisations action plans. There was a sense among the people I spoke to that health was a private matter between the patient and the doctor not something that was relevant to community work. Health or the lack of it was seen as good or bad luck. The following excerpt from field notes shows that while health may not be seen as an object for community work prescription can be also something of a community endeavour. Nevertheless access to medical care through the medical card is seen as vital.

SL: Just, people are not health conscious.

FOR: And I mean when they're sick they just wait until it's time to get the prescription and then they go to the doctor?

SL: Oh, they don't always go to the doctor. People exchange tablets here all the time.

FOR: Do they?

SL: Oh Jaysus.

FOR: Antibiotics and...

SL: Oh all sorts of stuff, oh yeah. I remember being in the flats. I used to live in the flats in Sheriff Street and you'd hear – "Lyniee" across the flats, "What do you want Caroline", "Have you any Ponston?", "have you any Roche?" Have you any this, that, any of that? It happens quite a lot, and generally speaking yeah, of course, the

people go to the normal doctor when they're at the various stages but, if you haven't got the money, if you haven't got a medical card you're snookered."

ICON 5th Conference Kilkenny2006

At the start of my field work most of the community groups and residents did not know what was meant by the term "Primary Care" nor did they see doctors as relevant to community work. I was constantly asked to explain what Primary Care meant. By the end of my field work a number of initiatives occurring in parallel prompted the community sector in the north east inner city to establish a Health Action Forum (HAF), not least of which was my presence as researcher exploring issues of community involvement in Primary Care. The development of the HAF was in some ways an unintended consequence of my collaboration with UISCE, the Mountjoy Street Family Practice and the Participation and Practice of Rights Project (described in chapter 7) which focused attention on health. In 2006 ICON held a major conference to set an action plan for the next three years. The priority for health action came out of the drugs treatment workshop attended by UISCE and myself (March 2006 ICON conference).

The establishment of the forum was not easy as interest was not high among ICON members. Early in 2007 ICON invited all interested members to come to a meeting about health. Only 12 to 15 people attended. I presented an analysis of my research in the north east inner city, which indicated a picture of relative poor health associated with deprivation. The Community Action Network (CAN), who facilitated the meeting, gave a presentation on the Social Determinants of health model. Subsequent meetings had fewer participants. Nevertheless, the Forum was established the terms of reference defined as:

> The ICON Health Forum is comprised of local community organisations and individuals living and working in the north east inner city who are exercising their right to participate in health and service development(ICON 2007b)

At this stage a new Primary Care Centre was being planned by the HSE. This gave focus to the establishment of the HAF which developed a proposal to conduct a 'community consultation' to assess community health needs and identify what services the community wanted it to provide. The HAF was successful in getting funding for and conducting the community consultation (Monaghan and McGrory 2008). The Forum engaged with the HSE through the Primary Care Development officer and the social inclusion Manager. They provided information about developments on request and came to meetings when invited.

Engagement between the HSE managers and the HAF saw the managers providing information. They did not make decisions, negotiate, or justify decisions made. At one meeting, the Primary Care manager informed the HAF that there were no plans for a needs assessment prior to the building of the Primary Care Centre, and that there were no plans to include community in the Primary Care Implementation team. When the ICON coordinator challenged this, pointing to the Primary Care Strategy requirement for a health needs assessment and community involvement, the manager asked that the forum to raise these issues with her direct boss (the Dublin North Central Local Health Office manager).

Missing space: participation in health service decision making

The cases above see the community sector engaged with health authority in temporary spaces, claimed in response to specific issues, which then closed once the issue was dealt with. On-going partnerships established for other reasons e.g. RAPID , Drugs Task Force gave community delegates access to health services managers as did the health service CDWs. Once the HAF was established there was more on going contact with the PC development manager and the social inclusion manager, however communications were information sharing only, as the managers did not appear to have decision making power.

The literature dictates that meaningful involvement centres on decision making (Burns, Haywood, Taylor, Wilde, and Wilson 2004;Coulter and Ellins 2006;Purdam and Crisp 2009). However it was difficult to see from my position in the community, where health services decision making actually occurred. From my participation in other space, I knew it was going on, but not at a local level. An 'Out of Hours' GP service was being negotiated between the north Dublin GPs and the HSE during this period. This would bring a new Primary Care service to the North Strand Health Centre in the north east inner city along with significant

refurbishment[20] but this occurred in a closed space from which the community were excluded. The development of the 'Grange Gorman Site' on the west of the city prompted the opening of a space in which the NWICN engaged with the HSE North West Local Health Office (LHO) about a proposed development of a Primary Care Centre.

[20] This was the health centre in which the Health Board General Manager of Community Care Area 7 and community delegates became involved in making minor physical changes

Decision making and power

Unoccupied Mountain View Court Local Authority flats. Site for proposed development of Primary Care Centre

In 2006 there were plans for development of health facilities in the north east of the city. A manager for the North Central Local Health Office presented the HSE plan to build a Primary Care Centre (PCC) on the old Mountain View Court site to the Dublin City councillors. In their presentation they made reference to the addiction services they planned to put in the new PCC, to which the councillors objected.

Making way for a new Primary Care Centre: The flats are demolished

My field notes reflect how news broke to the community sector about the plans for a Primary Care Centre (PCC) in the north east inner city (NEIC).

> T just got news from SL (ICON Chair) (who had just returned from a meeting with the CEO of the Dublin City Council), that there will be a new PCC with the full range of Primary Care services where Mountain View Court (Local Authority Flat Complex) currently stands. The DCC was preparing to invite tenders for demolition of the flat complex. Feeling that it would be a bone of contention, I asked if addiction services were to be included in the new development. T said 'no'. He said that the 'Area Plans' were presented to the meeting of councillors who voted in favour of the PCC and against addiction services being part of it.
>
> "So where will they be?" I asked
>
> "Well they (HSE) still have a lease on the building (drug treatment clinic - City Clinic)" T replied indicating that they would probably stay where they were. (Field notes July2006).

The news about the PCC was welcomed by ICON. How the news broke raised a number of questions for me about the HSEs engagement mechanisms with the community and local

Primary Care providers as well as about how planning was done and decisions were made in the HSE.

While policy dictated that Primary Care developments would be based on the assessment of need none had been conducted in the north inner city Dublin:

> Needs assessments should specifically identify special needs or areas of disadvantage to ensure that Primary Care teams can be targeted to meet those needs. (Department of Health and Children 2001a)

The issue of addiction services becoming a part of the new Primary Care Centre became a sensitive one. Primary Care in the new HSE structure came under the Primary Community and Continuing Care (PCCC) directorate as did addiction services. There was good argument for addiction services to be part of the Centre. There was precedence in that the pilot Primary Care Centre in Ballymun (another deprived area of north Dublin), provided some addiction services (namely methadone prescription). The local health centres in the north east inner city already provided some level of addiction services (Summer Hill centre provided needle exchange and North Strand needle exchange and methadone prescription).

However the councillors believed it to be wholly inappropriate to put addiction services (which they equated with the City Clinic) beside a Day care for the elderly, as one of the councillors explained:

> *Councillor: The Health Board put that proposal to the City Council without consultation with the public representatives. Total and utter disaster! But you can take it from me Fiona it's not going to happen*
>
> *Fiona : What's the reason for that?*
>
> *Councillor: Cos we've suffered enough. Can you imagine putting an addiction service next door to a service for the elderly? Now who in the name of Jesus in the health services drew up that plan!*

Fiona: That is there. In the strategy, that they all go together in the Primary Care Units.

Councillor: No it can', it can't. There has to be an ostracisation of addiction on stand alone. You can't put in addiction, and it will threaten services for the elderly.

He pointed to the history of local social conflict in the battle against drugs:

Councillor: That whole area that's where it started 12 years ago in Mountain View Court that's where the women marched 12 years ago this month. From Mountain View Court down to Killarney court and said "we're takin' no more."
You put addiction services in there into an area that has been concentrated with social issues, addiction, muggings you name it. Its .. a recipe for disaster!

He said that when the HSE had presented the proposal to the City Council the councillors had 'created havoc' and that the proposal was now 'off the table'.

The councillors believed they were speaking for the local community. ICON agreed with their view. SL felt that ICONs members agreed with this stance. However the ICON Health Action forum conducted a consultation with the community over the next year which asked people in the area what they would like to see as part of a Primary Care Centre. Findings show that there were varied views on whether there should be addiction services as part of the centre. While there was a strong minority opposing a service most of those consulted had no objection to general services such as methadone prescription and counselling. Most were against dispensing of methadone on site (Monaghan and McGrory 2008)

Though the health authority had not come under the Local Authorities its managers did not challenge the councillor's decision or authority to make such a decision. At a meeting with (almost a year later) the HAF the Primary Care Manager confirmed that other arrangements for addiction services were being sought, as the meeting minutes reflected;

> In relation to addiction services the HSE proposal to integrate addiction services into the PHCU in Mountain View were rejected at the Area Committee. Changes to the City Clinic are now being sought but there are no concrete plans in place. (ICON 2007b)

Conversations I had with managers in the addiction services suggested that the HSE would not 'rock the boat' with the councillors but was planning to keep a couple of consultation rooms in case services could be 'slipped in' at a later date.

Without the insights of my inside sources, it would have appeared that the HSE managers had decided to follow the councillors' wishes. However, with this information, I found it hard to determine whether a concrete decision had been made.

An analysis of power

Using Dahl's (1957) one dimensional view of power sees the councillors (on behalf of the community) as exercising power. Both parties stated what they wanted and the councillors got the HSE to do their will. However as Lukes (2005) points out the one dimensional view requires people to state what they would do. It transpired (albeit with insider information) that the HSE did not declare out rightly what they would or would not do, rather they allowed the councillors to assume that addiction services were 'off the table'. The information at the HAF was cleverly ambiguous and does not actually say whether the HSE had made a decision at all. The decision was left open to see what might be done later. According to Walt non-decision making may mean that issues fail to enter the policy making processes because they are against the interests of those in power (Walt 2006). The councillor's interests were in conflict with the HSE's. Allowing the councillors to assume that their will would be done, meant that the issue was not open to further discussion which might bring in overwhelming support for the councillors' position from the community. This had the potential to increase conflict to a point that the HSE's interest would not have a chance. The HSE in public were accepting the councillors' decision but in private they were not making one.

Two dimensional power takes account of the fact that decisions are not always made. According to Bachrach and Baratz (1962;1970), where a group or person creates or reinforces barriers to the public airing of policy conflicts, that person or group has power. This view sees the HSE as exercising power in their masking of the fact that they had not conclusively made a decision. Bachrach and Baratz see a 'non-decision' as,

> 'a decision that results in suppression or thwarting of a latent or manifest challenge to the values or interests of the decision-maker'

This is a means by which demands for change in the allocation of benefits and privileges in the community can be kept covert (Lukes 1974).

Covert decision making in the context of drug treatment policy is not unusual. The HSE's non-confrontational approach is reminiscent of the development of addiction policy and which had been far from transparent (Butler 2002). Covert policy making had too been a constant feature of English addiction services referring to `the separation between the debate conducted in public and that conducted in policy networks' and to `a certain fear that too much public involvement in discussions might inhibit intelligent policy making' (MacGregor and Smith 1998).

However there is more going on than conflict between councillors and the HSE. There is the unchallenged position of the councillors not only by the HSE but also by those who their decision affects the most- the addiction service users. This is potentially a 'latent conflict' which community groups, networks and partnerships did not appear to wish to exploit. According to Lukes (1974), Bachrach and Baratz's analysis does not deal with situations where there is neither over or cover conflict. Also their analysis requires decisions. Non-decisions are even defined as decisions of a certain type. However Lukes points out that there are forms of exclusion which require no conscious choice between alternatives or decision. He says that the most effective and insidious use of power is to prevent conflict arising in the first place (Lukes 1974).In these cases the three dimensional view is required. This is a thorough critique of the first two forms which allows for the many ways in which potential issues are kept out of politics, whether through the operation of social forces and institutional practices, or through individuals' decisions' (Lukes 1974).

Drug service users did not object to the councillor's insistence that they would be excluded from the new Primary Care Centre. They were non-aware of the decision. Both the HSE and community for opposite reasons suppressed the issue and potential conflict of interests involving drugs service users was averted. Lukes' definition of 'latent conflict' applies, in this case, to the interests of those exercising power (councillors and supporting community sector) and the real interests of those they exclude (drugs service users). This form of power operates through internalisation of powerlessness or through domination ideology values and forms of

behaviour (Gaventa 2006). Services for 'addicts' had been ruled out without involving 'addicts' in the discussion (or indeed the broader community outside representatives).

In summary therefor, in the one dimensional view of power councillors were exercising power, in the two dimensional view the HSE by masking non decision making was exercising power and excluding the interests of community. In the third view councillors and supporting community were exercising power. The first dimension of power can be discounted, as it required actual decision making to be explicit, which it was not. The other two analyses are valid and see HSE as more powerful when it comes to health care decision making, than the community representatives exercising power to exclude drug users from community services. The Drug Service users, whose service hung in the balance, did not get to express an opinion, a desire, or a grievance. The end result is at best a substandard service for drug users by virtue of the way it has to be planned: 'a couple of rooms', 'slipped in' later.

Unfortunately the poor image the community had of addiction services (congregation of 'addicts' outside the drug treatment clinic) may also have had something to do with the perceived need to create services covertly. These images influenced opinions of what was acceptable in a new Primary Care Centre. The covert approach was considered pragmatic in the 1990s. Services being established were a radical change to what went before, however it is harder to justify this approach in 2006 when drug treatment in Primary Care was well established. Though well established, the majority of the people registered to receive methadone on the Central Drug Treatment List (CTL) did so from a health authority Clinic. In many areas including the north east inner city GP practices were reluctant to provide methadone to those with opiate addiction. This fact did nothing to alleviate the overcrowding at the treatment clinic[21]. It appeared that GPs, councillors, and community wanted treatment of 'addicts' segregated.

The debate about what services should be provided was taken out of the public arena. In the event no decision had to be made, at least in public anyway. The recession took effect on

[21] My analysis showed that only 2 of the 14 GPs in the north east inner city registered as members of the NICP were part of the methadone protocol.

capital funding, and a decision was made somewhere in obscurity that no Primary Care Centre would be developed.

Discussion: Spaces, decisions and definition

While the community organisation, through groups and networks, improved participation and influence by the community sector in local policy and decision making in a range of sectors including housing regeneration, education and drugs, it did not appear to do so in health decision and policy making in any significant way. There was an absence of a space where local community could engage at a decision making level with the health authority. Prior to the abolition of the Health Boards in 2005, the Northern Area Health Board (NAHB) had provided a space for involvement of elected representatives. This allowed some access of local groups through politicians to HB decision makers (case study defending the treatment rights of drug users). Interestingly, even after the abolition of the NAHB, elected representatives were still 'calling the shots' (saying 'no' to addiction services in the new Primary Care Centre). The seemingly contradictory stance of both these cases is contextualised by a complex set of social relations in a community which has just about survived significant trauma as a result of drugs. What is acceptable in this context is clear to those who have been through it, but remains obscure to those who have not.

Access to an identifiable locus of decision making is a prerequisite for community involvement. The lack of development of health services until the proposal to build the Primary Care Centres meant there were no external stimuli to prompt communities to demand involvement. Neither was there a system to monitor community's health status which may have prompted a reaction.

GPs provided services to community members but did not have a relationship with the community efforts to tackle underlying determinants of health according to the social health model. They were not represented on any of the local spaces for participation. As we saw from the previous section they were not seen as relevant to the community agenda. The services which came under the remit of the health authority did have a relationship with the community where the community demanded it, e.g. drug treatment clinic, and through partnership spaces. The health authority is also a significant funder of the community and voluntary sector (Weafer and Weafer 2004).

Defined according to the social model of health, the community were very much involved in Primary Care using a community development approach to tackle identified needs. These included all layers of Whitehead and Dahlgren's model (figure 4): environmental conditions, living and work conditions, social and community networks, and lifestyle factors. Though these determinants of health made up the work of the community sector it was not done under the banner of health or viewed as health. Defined in terms of health services, the community were not involved in Primary Care decision making.

One of the ten Primary Care demonstration projects developed a model for community involvement in Primary Care using a community development approach (Lifford /Castlefinn area, Donegal) (Sutherland 2004). Many of the outcomes achieved address social needs identified in the needs assessment e.g. a carers group, a youth club, play areas and so on. The model also claims impact on service design and delivery, with increased health workers made available to the PCT, better organisation and increased and more appropriate services. However, this was also a result of the resources put into the 'demonstration' projects and the fact that the participation model was established and supported from within the health services, inviting participation from the community. A community development model was used in Lifford/Castlefinn which with adequate resources and backing from the HSE and the Combat Poverty Agency was deemed successful(HSE and CPA 2006). However the report describing successful outcomes of participation in Primary Care is very clear that funding for participation is central to success, and that guidelines for community participation should have 'an attached budget'.

In the north inner city the social needs were addressed through the community organised structures without involvement in Primary Care. A HAF was established by ICON which succeeded in producing a health needs analysis but was not as yet given access to Primary Care decision making or permitted to become involved in establishing PCTs. At best, it can only be said therefore, that the community development approach to community involvement in PC was successful in the context of invitation and support from the health authority.

The type of participation seen in this section is by and large what Morgan calls 'conventional participation' which ironically needs the cooperation of the state. Though unconventional

participation was utilised from time to time by the community sector (protest, non-participation), 'conventional participation' is supported by a community development approach which is dependent largely on government resources. The irony is that the ideology which supports people coming together 'doing it for themselves' is helpless without dependence on the state. The paradox continues with observations that participation is unnecessary and unwarranted where relations between state and citizen is more cooperative and mutually respectful or 'where the citizens are the state' (Morgan 1993).

Though coming together in the form of networks strengthened influence when all member groups had a way of being represented, what representation itself means requires further attention. In assessing representation, Cornwall asks of spaces for change, who participates and who is excluded? How and by whom are different actors represented? Do people hold unelected officials, whether committee members or local bureaucrats to account, and how?

The networks themselves found a need to improve routes to decision making for people within groups represented by the networks, but who are not on management committees (ICON and NWICN 2008). There are people who exclude themselves from spaces of collective voice or association, who may lack a sense of themselves as any kind of collective entity: those who rarely represent themselves directly but who are spoken for and about. Cornwall (2002) says that these "missing persons" may be the very people that agencies and services most want to support In the context of health, involvement in decision making and north inner city Dublin, the missing people in this case were drug service users.

The next section focuses on the drug users and their views on health services in an attempt to provide voice to those who are less likely to demand it.

Chapter 8 Involving drug users

This section focuses on drug users[22], arguably one of the most marginalised groups in society and their relationship with health services. It opens with a discussion which presents what I describe as a 'folktale' which frames this chapter. The first section provides context in terms of the drug services, the second presents the action research project which aimed to influence health service decision making. The third evaluates this approach as a 'claimed space' for participation and discusses power relations in this domain.

> We were getting ready to start the first focus group in the bright spacious room that the SAOL drug rehabilitation project had made available to us. It was a hot summer's day, so we opened windows, allowing the noise of traffic from the busy city street fill the room. ER was downstairs in the kitchen making tea for the participants as they were coming in to the building. People were arriving in ones and twos. CF[23] and I were getting the room ready for the focus group participants. CF told me a story about a friend of his who had recently had an abscess on her upper arm lanced. His friend like CF himself had a long history of intravenous heroin use. CF said his friend's experience was not uncommon among drug users.
>
> The story went: a friend of his had an abscess on her arm[24]. It was getting redder and bigger and as it was coming into summer and she would be wearing short sleeves she didn't want it showing. She didn't want people knowing "what she was". She decided to go to the hospital. They said it needed to be lanced. And there and then they did it. CF said they lanced it with an 'X' shaped incision. This CF told me in a matter of fact manner that this was done to mark you as a drug user for other health workers. (Field notes June 2004)

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[22] I use this term to refer to mainly opiate users, though generally poly- drug users heroin addicts have largely been subsumed under the state methadone programme (see Saris J and O'Reilly F, (Saris and O'Reilly 2010)

[23] CF was a sessional worker for UISCE. He died in 2008 from drug related causes.

[24] A build-up of puss under the skin caused by bacteria already on the skin and/or irritants in the drug usually occurs if skin popping or after a 'missed hit'.

The treatment of abscesses was discussed during the focus groups. Some participants complained that proper care was not taken during treatment. In one group they agreed it was better to treat abscesses yourself than being "butchered".

> *When they cleaned up my abscess she just got the blade and when they done that I said will you just put a little hole. She wouldn't, she just cut across it. Like an 'x', that's to say – you are on drugs (FG1 P6)*

> *Personally I don't know anyone that has gone in there to have an abscess done that hasn't come out with a scar...a huge scar. (FG3 P6)*

> *I had one here and they sliced it 3 or 4 times before they actually punctured the abscess, trying to relieve the pressure, but they scarred me pretty bad there I Thought. Look you can see it there. (FG2 P5)*

I found it hard to believe what I was hearing and wondered about the so called 'objective' reality of what was being claimed. I asked a doctor who treats drug users and has lanced many abscesses how this was done. He said that it depended on the abscess size and position but confirmed that an 'x' like incision was one option. He too was shocked to discover that the drug users felt that they were being marked as drug users.

Treating this story as one of Fetterman's folktales or anecdotes is instructive. He says that these are present in all settings and can be quite informative about a culture;

> Folktales are usually drawn on familiar surroundings on figures relevant to the local setting, but the stories themselves are facades. Beneath the thin veneer is another layer of meaning. The inner layer reveals the stories' underlying values (Fetterman 1998).

The lancing of the abscess story has, as Fetterman found on occasion, contained "more than a grain of truth" when one considers what would be necessary for this perception to survive. If explanation about the procedure that takes place and the resultant scarring was a matter of course between health professional and patient prior to an incision, and if the patient was

then invited to ask questions and provided with choice about the course of action, it would not be possible for such a story to survive. It may be inconceivable to think that a health professional would intentionally 'mark' a person for identification by another health professional. Yet it is less inconceivable to think that a busy health professional, who sees a drug user's abscess as 'self-inflicted', would get on with the job, incise the abscess without much information explanation or dialogue. Neither is it inconceivable to think that a down-trodden perhaps inarticulate drug user without much confidence or self-esteem would not demand to know exactly what procedure and technique would be used and the size and permanence of the resulting scar, prior to any incision. With only slight shifts in perspective, a scenario where a patient leaves a health service with an 'X' shaped scar and the space to believe anything about the reason for the marking, becomes conceivable.

This perception of reality crystallises the way drug users see themselves as being viewed in the health system. This story reinforces their sub-cultural belief that they are seen as unworthy of the same treatment as non-drug users, blamed for their ills, as "filth" or "diseased" and labelled as such by the health services.

The context of drug treatment in the north inner city

The policies and structures in place in the early days of illicit drug use in Ireland were seriously deficient. They followed the system in Britain, were conservative and centralised, with a central treatment agency established at Jervis Street under the clinical direction of a consultant psychiatrist. In 1988 following the closure of Jervis Street clinic the National Treatment and Rehabilitation Board (NTRB), widely known as Trinity Court, moved to Pearse Street. Over the next decade services and policy changed from a service that was centralised and specialised with an ideology tending towards abstinence models to the institutionalisation of regulated methadone prescribing by general practitioners. The introduction of the methadone protocol was seen as a pragmatic success albeit one that was necessarily covert in process (Butler 2002;Saris 2008).

GPs had no role in the initial services and the psychiatric services saw no role for them, stating that they were 'not in favour of the treatment by GPs of 'drug addicts'(Department of Health 1984). GPs were wary of involvement with drug users. However a small group felt that they could not ignore the problem and supported the view that methadone maintenance at Primary

Care level was legitimate and was 'evidence based practice'. Over time this view became accepted and the Irish College of General Practitioners (ICGP) in 1990 produced a policy statement on the management of problem drug users in general practice (ICGP 1990). A formal protocol for methadone prescribing by GPs was published in 1993 (Department of Health and Children 1993). In 1997 the ICGP produced guidelines for its members which were updated in 2006 (Irish College of General Practitioners (ICGP) 2003). Since 1998 legislative and administrative regulations to control the prescribing and dispensing of methadone were in place (Department of Health and Children 1998;Government of Ireland 1998).

Together with the Eastern Health Board it urged its members to treat drug users in their localities (Department of Health and Children 1998). At the time of study one-third of patients on Methadone Maintenance Therapy (MMT) attended a general practice for their treatment (Long 2008).

While such developments were generally welcome at the local level, they were not without critics. In many neighbourhoods where drug users were concentrated, for example, this proliferation of addiction services was experienced by some community members as an index of the community's distress, as much as it was seen by other community members as helping some of the community's most vulnerable members (Saris and Bartley 2002).

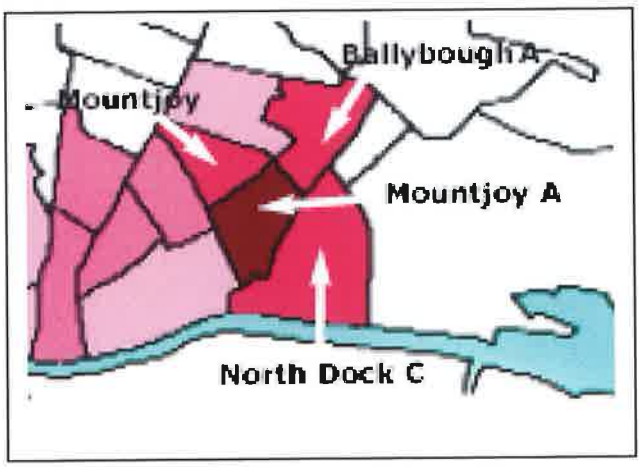
The local context

As seen in table 6 below the electoral divisions (EDs) with the highest number of residents on the Central Treatment List (CTL) are within the north east inner city. Figure 19 shows the high concentration or those on methadone in one locale in the centre of the ICON area. This data reflects point prevalence in 2004 and 2006. This CTL data represents the most reliable data for people in treatment. The data below shows that in one ED (Mountjoy A) 1 in 20 residents were registered on the CTL as in receipt of methadone.

Table 6 Methadone clients by area of residence in the ICON area

Service Users: Methadone Protocol				per 1000 population* (2002 census)	
Ward (ED) Name	*Nov. 2004*	*March 2006*	Pop. 2002	2004	2006
Ballybough A	103	94	3,368	31	28
Ballybough B	33	38	3,045	11	12
Drumcondra South B	6	8	1,392	4	6
Mountjoy A	164	154	3,158	52	49
Mountjoy B	73	69	2,739	27	25
North City	43	43	3,967	11	11
North Dock A	7	7	1,292	5	5
North Dock B	20	16	3,598	6	4
North Dock C	89	83	3,516	25	24
Rotunda A	69	57	4,267	16	13
Rotunda B	37	35	1,770	21	20
Total (NEIC)	644	604	54,133	12	11

Figure 19 Electoral division areas with high prevalence of people on methadone



Services

A range of services for people with opiate addiction is provided by community, voluntary, statutory, and private sector organisations (table 8). The drug projects available for drug users

in the north inner city in the ICON area are listed and described in Table 8. In general projects such as these are identified locally through the community groups' network organisation and supported through the drug task force. As the table shows, the health authority acts as an important funder of local projects. The health authority also provides treatment services in the form of the methadone protocol. Treatment options offered include stabilisation, maintenance, reduction and detoxification are available in the City Clinic and the satellite clinic in the area. Corollary services such as counselling, viral screening and psychiatry services are provided as part of these services.

Extent of GPs participation

In the Eastern Regional Health Authority (ERHA) area, the numbers of patients on the Central Treatment List doubled from just over 3000 in 1998 to over 6000 in 2004. Thirty per cent were treated in General Practice in the ERHA in 1998; this rose to 37% six years later. The participation of GPs in Primary Care in the scheme is vital as it means there is progression of stable users from treatment centres and specialised clinics to Primary Care where all their health needs can be addressed. This transfer then frees places for cases with more serious addiction problems.

According to the Central Treatment List (CTL) figures, only 16% of people on methadone and resident in the 35 EDs in the North inner city area were receiving methadone from GP Practices (i.e. not Health Board Clinics). Though the number of NICP GPs participating in the Methadone treatment protocol has doubled (7 to 14) since 1998 this is still only a minority (28%). Though GP professional bodies and Health Boards have recommended treatment of drug users in the community and GPs receive substantial additional payment for their treatment, numbers agreeing to treat this group are low. Indeed at 16%, far fewer receive treatment from GPs in the north inner city (an area of high opiate addiction) than in the ERHA as a whole (38%). In the north east inner city only 2 of the 14 GPs registered with the NICP and based in the area were part of the methadone protocol.

Table 7 Community Based Drugs Projects

Project	Service	Funding Source
After Care Recovery Group (ACRG)	Service: Practical support to those in recovery. Drug free project that offers a day programme. Non-therapeutic, non-medical, access to counselling, access to further education/training, care parenting skills, relaxation techniques, anger management, etc.	HSE
Crinan Youth Project	Service: Treatment and rehabilitation project for young people (15 – 21 years) from the North Inner City, with drug dependency. Educational, recreational and therapeutic programmes.	HSE
SAOL Project	Service: Rehabilitation project for women drug users through personal development, education and support. Participants commit to a two-development programme attending 5 mornings per week.	HSE, FAS
UISCE (Union for improved Services, Communication and Education)	Drug service Users Forum. Provides an opportunity for those in receipt of services to have a role in policy development. Services include: Hosting drug service users fora; providing information by regular newsletter; conducting action research on issues with users.	HSE through DTF
ICON Drugs Support Project	Service: Drug referral, immediate response and support.	HSE, CDUSB through DTF
CAIRDE	Service: Support for people infected or affected by HIV/AIDS. Crisis intervention, information, referral service, counselling, child and family service, volunteer support and befriending, advocacy and campaigning.	HSE
Oasis Counselling Services	Service: Bereavement counselling on one to one basis and families	HSE
North Inner City ASESP	Service: Education and skills training to children age 13 to 18 years.	HSE, FAS
North-East Inner City Community Policing Forum (CPA)	The Community Policing Forum is a community-led response to address the issues of drug dealing and antisocial behaviour. The CPF acts as a link between the community and the statutory bodies and public representatives.	DCC Through DTF
Hope	Service: Education and prevention programmes for parents in relation to problem drug use.	HSE

Creating a space for involving drug users

In June 2004, through ICON, I was introduced to the Participation and Practice of Rights project (PPR) [25]. The project worker (TR) was planning to consult drug users through UISCE to find out more about their experience of health and housing in the inner city. This was the pilot phase of the PPR project which hoped to achieve funding for a three year project which was aimed at advancing social and economic rights in disadvantaged communities through a rights based approach. At this point (TR) had made contact with UISCE[26] to help him access drugs service user views.

There was an overlap between the information the PPR wanted to collect and that which I was interested in exploring. I agreed to lend my research experience to supporting the collection of the required data. I hoped that proximity through this assessment would allow me to gain an understanding of how a socially marginalised group such as drug users experienced health and health services. I wanted to know if they had opportunities to influence health services decision making and whether as the Health Strategy promised they were encouraged to have their say, were listened to , that their views were taken into account (Department of Health and Children 2001c). As part of the general healthcare system patients are encouraged to actively participate in decisions about their own treatment as well as input into policy decisions about the treatment service itself (Department of Health and Children and HSE 2008). I wanted to see if this applied to marginalised groups. I suggested the involvement of the AOC's GP Practice as I thought it would be of benefit when it came to influencing health

[25] The Participation and Practice of Rights project (PPR) grew out of an all Ireland initiative. The central objective of the PPR was to encourage the communities in disadvantaged areas to use a rights based approach to redress many of the social and economic deficiencies, which affect them. The to focus on the rights of those who have been seen in the past in the most negative light by society, 'drug users' and therefore opted to listen to the voice of people receiving methadone for an opiate addiction.

[26] The Union for Improved Services Communication and Education (UISCE) is a group made up of users, ex-users and professionals who believe that the voice of the drug user is integral in the development of drug policy and in realising an effective treatment response. UISCE was formed as a result of a North Inner-City Drugs Task Force (NICDTF) initiative. The NICDTF is one of 14 local Drugs Task Forces in Ireland overseen by the National Drugs Strategy Team. Emily Reaper assisted by Christy Flood facilitated the group discussions.

services. The Mountjoy Street Practice was one on the few in the area involved in the Methadone Protocol[27].

The plan was for the three partners to follow a participatory action research approach,

Step 1: Assess views of drug users through focus groups

Step 2: Use findings with the participants to prioritise key issues to take to service providers.

Step 3: Present drug users priorities to a consortium of 'friendly insiders' and establish act issue possible solutions and channel or route to policy or practice change.

Step 4: Follow identified actions as they occurred and monitor outcomes.

The partners met after each step and before and after presentations. It was agreed that the project would be time bound to a period of two years.

Step 1: Voices of drug users: Focus Groups

Participants were selected by UISCE who asked for volunteers among those outside City Clinic and meeting drug users in the street. Twenty five drug users agreed to take part in discussions and three groups were held on three consecutive days in July 2004. The venue for the group discussions was the SAOL building on Amiens Street. This is a venue known to most of the group participants and was convenient as it is situated across the street from Amiens Street City Clinic, the drug treatment centre where most of the group participants receive their methadone. SAOL is a drug rehabilitation project for women and has a crèche, which was available for the participant's children.

I designed the question route in collaboration with UISCE staff. Groups were moderated by ER and CF UISCE members who were also drug users themselves. Participation was voluntary and

[27] This is a GP run family practice, which aims to provide quality Primary Care services which are appropriate, affordable, accessible, and acceptable to all members of the local community. The practice has a special interest in opposing discrimination in all its forms. The practice has a large group of patients receiving methadone maintenance services and has an interest in listening to the views and voice of particularly marginalised groups such as homeless people and drug users. The practice was awarded a research grant by the Royal College of Surgeons in Ireland to assist with practice research projects. Collaboration in this action research project is one such project. The Mountjoy Street Family Practice provided financial and technical support.

participants gave permission for the findings to be published. Confidentiality was assured and first names only were used to protect the participant's identity. Names were changed in transcripts.

Four months after the initial focus groups participants were asked to re convene to verify the initial findings and to prioritise problems with services. Thirteen of the original 25 focus group participants reconvened for the 'feedback' session.

While the report produced as part of this action research presents the findings were presented by service type to facilitate identification of appropriate sites to influence policy change. Below are the findings under the themes which emerged under the categories of context, views, and recommendations:

Context: Poor living conditions

While the focus of the group discussions stimulated a discussion of health and health services, participants identified housing as a priority need. Of the 25 participants involved in the focus groups, 13 were or had at some time in the past, been homeless. The length of time using drugs ranged from 1.5 years to 18 years with an average of 11 years

The Housing (Miscellaneous Provisions) Act 1997 permitted local authorities to act against tenants exhibiting anti-social behaviour by serving them with an "excluding order". This provision required a court ruling on eviction of an offending tenant, and was intended to prevent the use of local authority houses and flats by proven drug dealers to carry out their dealing (Murphy-Lawless 2002). However, the excluding order was used not only in these cases, and influenced exclusion without having to be used. Drug users were leaving voluntarily so that their family would not be faced with eviction, or so that it would not come to eviction, thus avoiding permanent exclusion from the housing register. In a study I conducted with AOC we found that the proportion of current or past drug users among the homeless population (64%) had doubled in the inner city over the previous 8 years (O'Carroll and O'Reilly 2008b). One participant described the effect of this policy;

> *I was an 'anti-social behaviour' (eviction) that's why I was in a hostel so long... they had me barred from the housing list for 10 years and anyone who took me in was evicted as well. That's how I was in and out of B&B's. That's all still on my record, I'm only a*

subtenant. My husband's the tenant. They said I will never be a tenant; I will always only be a sub tenant. So if anything ever happened to my husband ... I would have nowhere to go. (FG1 P3)

While for most, drug use preceded homelessness, there were two men who started drug use having become homeless first. Both of these men had been homeless since childhood.

I'm a single fella, no kids. I've always been homeless. Since I was 10 or 11. Then when I turned 18, I put my name on the housing list. I'm 22 now. I have nowhere at all. (FG3 P1)

One of these men, now 22 years old, had started using drugs at a very young age and was addicted to heroin by the age of 15 years. At the time he tried to get on a methadone treatment programme in one of the clinics but says he was too young.

I had to go back on the streets. They wouldn't let me on. Maybe if they had I wouldn't be sittin' here now (FG3 P1)

Some of the participants who had been housed gave information about their living environment.

The house I got is falling to pieces. When the kids are having a shower the water pours down into the sitting room. There is a big crack in the ceiling. The plugs are all smashed, the light fittings all have to be fixed. The switch for the cooker is broke. Every time we touch it we get a shock. Out in the back I have the main sewage and that is blocked half the time and it pours out all over the back. Anyway it's not for the want of complaining, I complain all the time and I get nowhere (FG1 P4).

I have two young fellas; 16, 14 and a girl 6 and I'm still not housed. I'm living in a little one bedroom, in a landlord's house. I'm waiting on a house. The toilet and all is broke. Sometimes I have to send the kids to me ma's to go to the toilet because mine's not working. There's nowhere to wash clothes. (FG2 P4)

Views of health services

There was a heavy use of secondary health care services i.e. hospitals, drug treatment clinics and detoxification centres. Participants clearly had many health problems and some spoke of having HIV and hepatitis. Others had taken overdoses, some accidentally and some intentionally. Primary Care services used for health were drug treatment centres, clinics and satellite clinics, GPs, Pharmacies, Dentists, Health Centres, Needle Exchanges and Drop In centres. Participants spoke about their experiences of treatment at these services and about how their treatment by the service made them feel. This is described under the following themes:

- *Its my business nobody else's: confidentiality*
- *More than Methadone: care for the 'whole person'*
- *We're people too: discrimination*
- *'We're full': difficulty in accessing services*
- *Where's the care in health care*

It's my business nobody else's : Confidentiality

Participants felt confidentiality was not assured in the clinics and that people who should not know their business did. They felt that others could hear what was going on in the counsellor's room, from outside. They also had a problem with General Assistants[28] (GA's) knowing what they considered personal details about them which they felt was none of their business. Participants believed that only medical staff in the clinic in which they were being treated should be privy to information about them.

> *The GA's know everything about you. I said something to the doctor over there and a GA came back to me 2 days later and said it back to me.(FG3 P4)*

> *My files were left open on the kitchen table upstairs where people have read them. The fella (GA) read my files and has come back to me an has told me about my urines, and how they've been clean... he got in too much into my personal life. He was able to tell me that my files were left open and he knew that I was clean now.(FG3 P8)*

[28] General Assistance is a cadre of worker within the drug clinics whose primary role is to supervise urine testing. This is primarily to ensure that the specimen is the clients and has not been smuggled in. GA's primary role is therefore to watch people urinate.

I think there's not enough privacy, if you go up to a counsellor. For instance, I was sitting outside waiting for my counsellor and there was someone in with her and I could hear everything they were saying, 'cause where you're sitting you can hear everything. That's why I won't go up to see my counsellor, 'cause I don't want people listening outside. They're out the door with their confidentiality anyway. (FG1 P6)

The doors are paper over there, and you're sitting right on top of the door.(FG2 P1)

One man expressed dissatisfaction at the lack of involvement in his own care.

They had a meeting about me, I wasn't at that meeting. I should have been there. They were talking about my life, no one else's, my problems. (FG1 P4)

Paula had been discharged from hospital after taking an overdose but would not go for counselling as she felt people outside would hear.

Everyone can hear your business in that place, so I just can't, I don't go anywhere even though I want to. You know what I mean, but that turns you off. (FG3 P6)

They're in contact with your GP, they put your GP wide... what you are. You think the GP doesn't know what you are. The GP knows every single thing. Cos,I asked my GP for something to help me sleep and he said "not with what you're on". (FG2 P8)

Uptake of counselling service in the drugs treatment clinics was affected by views on privacy as seen above; however, lack of councillors as an issue was expressed by a number of participants. There was a perceived need for counselling and an appreciation of it by some participants.

I don't want any tablets or anything I just want a bit of advice or someone to go to. He (the doctor) says to me about counselling. There's a waiting list for counsellors.(FG3 P4)

It's one to one and it's handy. It's a half hour a week but you can have an hour if you want. But it is good. (FG3 7)

One woman who was recently discharged from a psychiatric ward in an acute hospital was asked if she had gone for counselling in the drugs treatment clinic.

> *No, I won't go to counselling there. I took a breakdown last week-end and me ma had to send for (names friend present also). I did try and do something again [suicide]. But I think if I had a havin' counselling and was able to talk about things and address things, I think I wouldn't have done it. (FG2 P2)*
> *(Friend interrupts)*
> *She needed help and there was no help there for her. (FG2 P3)*

> *There's no one there at the week-end that can talk to you. You have to wait for an appointment. Jasus... You're nearly trying to do it [suicide] at that stage, and then you just let go ...and then ye do. It's all mad. (FG2 P2)*

More than methadone: Care for the 'whole person'

The fragmentation of care for participants was apparent from descriptions of their experiences of health services. Most were "on a clinic" and this meant they received methadone for their addiction and some related health services. However, the full range of Primary Care services was not always available for those attending clinics. Many found it difficult to get a GP and those who did would go to the GP for general health issues and the clinic for addiction related issues. The impression was that no one health service cared for the person as a whole but rather their ailments were divided up between the services. Significant ailments were falling between services with no one caring for critical aspects of the person's health. A number of participants complained that their other (non-addiction related) health issues were not catered for in the clinic, however it appeared that this was not experienced by all as some doctors would treat general health issues. The inconsistency of this treatment policy sometimes led to confrontation.

> *I was only in the place two weeks and I went up to get a headache tablet off the doctor. My own doctor wasn't on, so the other fella said, "I can't give you one 'cause I'm not your doctor." So I said "are you the doctor on call?" and he said he was. I said, "if you're the doctor on call and I call you out to the house you'd have to see me right? So you're*

the doctor on call in the clinic and I need to see you. I know I'm not your patient but all I'm looking for is a headache tablet." He said, "no I can't give you one." So with that I ended up snapping. I should have just walked out but I ended up snapping. (FG1 P6)

In another case the fact that John was on methadone maintenance meant that he had difficulty getting treatment for his alcohol problem.

I'm not on drugs; I just get my methadone from there. I was on drugs a long time ago. The only problem I have is a drink problem. And that's on top of my Hepatitis C.(FG2 P7)

On the other hand, a voluntary agency (Merchants Quay[29]) which provides services for drug users and homeless persons including a drop in; a health service; a dental service and a needle exchange. This was seen in a very positive light and described as a 'caring service'. Simple things like a cup of tea and a sandwich meant a lot. The needle exchange and dental service were much appreciated. Not all participants knew about the dental service and were very interested in finding out more.

I think I'd have been long dead only for them [Merchants Quay]... from staying on the streets, I used to go in there in the mornings to get tea and something to eat off them. I was able to sit there from 10 till 12 and 2 to 4, whereas I couldn't do that anywhere else. (FG1 P5)

They have actually a dentist service in it now and they're flying through people. You just go in and put your name down.(FG2 P4)

Merchants Quay are all right. They keep you there, and bring you next door for a cup of tea and all, a sandwich and that. (FG3 P2)

Many participants found it difficult to get good dental care which they found distressing; as one woman put it *"your teeth are everything"*.

[29] Established by the Franciscan Order at Merchants Quay in 1989, the Merchants Quay Project offers a range of services for people affected by drug use and homelessness.

I have to say it's very good... Now I got teeth taken out in prison. They just pull them out, that's it and send you back. Not a painkiller... forget about it. But up in Mercants Quay now they have all this and a new dentist and they're trying to bring in a chiropodist. (FG3 P8)

While the effectiveness of methadone maintenance treatment in reducing heroin use and associated problems including involvement in crime and reduced transmission of blood-borne viruses is well established *(Amato 2005;National Institute of Health/National Consensus Development Panelon Effective Medical Treatment of Opiate Addiction 1998;Ward and Richard 1999)*, there is a question about whether it is treatment or an 'adjunct to treatment' as pointed out earlier (Department of Health and Children 1993). In the clinical response to heroin use, often little else is offered for the multitude of social problems that come with opiate addiction. In fact it was seen as a substitute for treatment of the individual as a whole person. Marie described the drug treatment service as void of 'care' for the person as a whole:

They just treat you like you're on 'Phy[30]' and that's it. They don't treat you with respect, you're just a number.(FG2 P6)

Participants felt that methadone maintenance was not addressing their addiction needs. One participant saw benzodiazepine addiction as his main problem. There was no treatment protocol for this. GPs rarely prescribe benzodiazepines for a limited period, in reducing amounts, as a detoxification treatment.

I was admitted to Beaumont for tablets and heroin. The heroin cleared up but not the tablets. When I came out of the hospital I had a slip and straight away they put me back to square one. He put me right back up to me full dose, but still wouldn't give me any Valium[31]. I was left to look after me own Valium to buy them myself on the street. So I went on and on and on and on, eventually I just said fuck this! So I had to try

[30] The Local name for methadone derived from the brand name Physeptone

[31] Valium (diazepam) belongs to a group of drugs called benzodiazepines. Valium is used to treat anxiety disorders, alcohol withdrawal symptoms, or muscle spasms.

myself. So I was more or less sent out onto the street to buy Valium and come down So I tried them 3 or 4 times, didn't work.. I told him, so he only started me there. And this is going on about 3 year, and I was only started there a few days ago! (FG2 P9)

Participants expressed the desire to be free from drugs and seemed less than satisfied to continue on methadone indefinitely;

So what's the plan are we to be hobbling in here to get methadone when we're 65? (FG1 P2)

They felt there were not enough opportunities for detoxification or support to "come down off methadone", as one young woman put it.

I am asking them eight months to get me in to the hospital. I am after having problems with me kids and I am asking them for help to get me into hospital. I am on a 120mls of 'phy'. I've been on coke and I am asking them to get me into hospital to take me down to leave me on a certain amount that I'd be alright, to get me out of the environment for a while, so I stay away from cocaine. I don't want to lose me kids. I've had to give my youngest kid to my cousin, to take him for a couple of weeks. But that was arranged with her before someone reported me. They took one of my kids and left one of them with me. I've been asking them, eight months, nine months to get me in to hospital. They tell me to see counsellors, to see my doctor and I've done that and there's still no help. I am still going nowhere fast... there's nothing happening. (FG3 P7)

Another felt that the treatment centre could do more to help people come down off methadone.

They should encourage people to detox off their methadone, people who are doin' well on their methadone they should encourage them to get off it. Try to bring them on... (FG1 P4)

'We're people too': Discrimination

Participants felt they were discriminated against while in hospitals. Perceived 'discrimination' in one case led to more expedient treatment, nevertheless, it was being treated 'differently' which bothered this participant who was admitted quickly from casualty because he was an 'addict':

> *I was in a bad car crash a couple of months ago and I was lucky to live. But when I went into the hospital, at first they were grand, but I think the minute they hear you're a drug addict their attitude just changes altogether. Because there was a person, for instance, lying on a trolley for two days before, but the minute I came in to the accident and emergency, they just push me up into a ward. I think they were hoping that I would walk out of the hospital. At first they were concerned and they were coming to me every few minutes but the minute they heard drug addict they just more or less vanished and just forgot about me. As for my 'Phy' they were just leaving it till the last minute hoping that I'd walk out of the hospital. (FG2 P5)*

> *I think it's when they hear you're a drug addict they say why should we be taking up beds when ours is "self-inflicted". (FG1 P3)*

> *They say terrible things to you, and treat you like dirt. (FG3 P8)*

This need to feel 'ordinary', 'normal' or 'like anybody else' ran through each of the focus groups and appeared to be more important than the actual clinical treatment they were receiving. Participants in all three groups were unimpressed by the local general hospital (The Mater) largely because they felt they were discriminated against because of their drug using status.

> *They treat drug addicts a lot different there. I don't think they like drug addicts and I don't think they like taking ye in. (FG1 P1)*

> *They're real cheeky you know. They say "you wouldn't be here if you wasn't using drugs" and say ours is "self-inflicted". (FG2 P2).*

Much of the difference in treatment was put down to attitudes of staff and a perceived lack of sensitivity. They felt the sign in the front of the hospital for 'Infectious Disease' let everyone know the reason they were attending. They felt dirty and diseased when staff wore gowns and gloves and tried to move them along as fast as possible.

> *Do you know what's very bad about the hospital, the sign 'Infectious disease' clinic. That sign shouldn't be there. People are goin' to be saying "Jasus, he has AIDs, he has the Virus, he has HIV or he has hepatitis". It's a sign that's lit up. Like the sign that's over the door that says exit. You're labelled. There and then, you know what I mean; you're labelled. (FG3 P3)*

Others were particularly sensitive to being labelled by identifying stickers on their charts. Participants believed that they were to identify them as drug users.

> *They have that luminous sticker so the doctors know and nurses know immediately that you're drug related, once they see that sticker on your file which is wrong I think. I have often snuck in and taken the sticker off (FG 2 P7).*

> *I can tell you what it says on the red sticker 'caution hazardous risk'. (FG2 P1)*

> *This sticker is put on to your file so that the minute the doctor picks up your file he knows you're a drug user.(FG 1 P5)*

Discrimination was evident to participants in most services. Participants felt discriminated against by other services which they accessed as part of the general population. There was an impression that if dentists were aware the patient was an 'addict' or had HIV or Hepatitis C they would be turned away. There were varying experiences dependent on individual dentists.

> *I went to the dental hospital, they didn't treat me cos I'm an addict.* (FG3 P7)

Frank felt his difficulty in getting dental treatment was because of his HIV diagnosis; however he felt he was treated well in hospital when he eventually was seen.

I went to umpteen dentists and because I told the truth about my problem.. my disease.. you know ... and when I told them, they always came up with a different story... an excuse. "Ah we couldn't touch that, cause we'd be afraid, " and, "not with the medication you're on", and "we'd be very afraid. (FG2 P5)

Some participants received methadone at the community pharmacy on production of a prescription from their GP. They complained about treatment within pharmacies. However, there were positive experiences though isolated. Some participants felt mistrusted and uncomfortable. They felt their treatment was "discriminatory".

They'd be watching every move, you wouldn't feel comfortable. (FG2 P3)

You have to stand outside the door while the security guard gets it for you.(FG2 P5)

I was collecting a normal prescription and I wasn't allowed go in and get it. (FG2 P4)

This fella standin' on the door won't let you in, he says "what's your name" and he goes and collects your stuff, you're not even allowed in, you've to stand at the door while he goes in and collects your stuff for you. (FG1 P3)

Some participants spoke of signing contracts with pharmacies about rules and regulations; however they felt the contracts are there for the sole benefit of the pharmacist and not the client. One woman complained that she could not come in to get her methadone if anyone else was present in the pharmacy at the time.

If there's any one else in the chemist that's on drugs you've to walk out, so I was getting kicked off because there was people in there when I was, that were on drugs. (FG1 P7)

One service that was regarded positively by all was the needle exchange. The only complaint about needle exchange raised was the fact that there are not enough of them. In north inner city Dublin there is only 7 hours of needle exchange per week.

They (staff) were real nice and supportive, they tell you what to do.... to mind your self... what you're taking.(FG1 P7)

'We're full': Difficulties in accessing Primary Care

Discrimination was closely linked to access to services. The medical card entitles eligible persons to access free health care. Medical cards give people access to a range of services: GP services, prescribed drugs and medicines, public hospital services, dental services, optical services, aural services, maternity and infant care services, a range of community care and personal social services - all free of charge (Government of Ireland 2004b).Only 12 of the 25 participants had current medical cards. Those without medical cards (the most vunerable) are denied access to GP services, dental services, and free medicines. To get a medical card, application forms have first to be completed then signed by a GP (indicating that the GP is willing to register the applicant as a patient). The form must be sent in to the health authority. The applicant is then informed of the decision by post. There are numerous points along this process which are potential obstacles to access to health care. By and large however the biggest barrier seemed to be in getting a doctor to register drug users as patients. Effectively the GPs act as the gate keeper, if s/he refuses then s/he is also refusing the patient access to free medicines and dental care.

I couldn't get a dentist because I had no medical card and no doctor would take me on.(FG1 P3).

The link between having no medical card and dental service was made by a number of participants.

I was told I was getting it done and by the time my appointment came round my medical card was out of date.(FG2 P7)

I couldn't get a dentist 'cause I had no medical card and no doctor would take me on.(FG1 P3)

Lack of access to GPs arose as a significant issue with many participants saying that they were constantly being refused by GPs. The common reason participants were given for refusal by GPs was that their 'list was full'. Participants pointed out that other people would be taken on

by the GP after they had been refused. Some found they would be taken on by GPs if they lied about their drug status.

> *I've had (names doctor) for years right, and then when I went to her, I said "doctor will ye take me back on? ..me and the little one, cause me ma's medical card is for her and (names two others)" She said, "ah no, I'm full up" and I was after hearin' she was after takin' people on. But I think it was because she knew that I was on drugs, that she didn't want to know. When I was younger and I wasn't on drugs, she had me. She just said 'I'm full' and she wasn't, so I just left it. I just kind of got annoyed; I just said ah "fuck it" I know I shouldn't, you know what I mean, I do need a medical card. So I'll just have to find a new doctor now.(FG1 P1)*

Other participants agree that this particular doctor's list is not full;

> *She only took my ma on, just there a few weeks ago. (FG3 P6)*

> *I don't have a medical card, I have the form I'm just waitin' on a doctor. Same as (names participant above)... she's me family doctor for years. I'm still waiting for a doctor. My job has been ringing up looking for doctors as well. (FG3 P4)*

> *Soon as they found out I was addicted to drugs in the past well one of them said "you wont be getting any sleepers off me" and that's when I stood up and said "stick your surgery". (FG1 P5)*

> *I've no medical card and I haven't had one in about 5 years because when I came out of Mountjoy (prison) I did put in for one and went to a few doctors and they just said "ah we're not taking you on, you'll want drugs off us". (FG 3 P5)*

Having no fixed address was seen as a barrier to getting a medical card by homeless drug users.

> *The medical cards [section of the Health Board] won't renew it on account of me not having a stable address. I'm not down as a corporation address so I can't go down as a family member, I'm goin' down as a single bloke, homeless. (FG3 P5)*

I've been 16 years homeless so I haven't had one (medical card).. 'No fixed abode'.*(FG3 P2)*

Patrick went on to say he had recently been housed and he had now applied for a card and had filled in all the forms. He had not managed to get a doctor; he said that one had refused him because of his drug use. When he was asked how this made him feel he just shrugged:

16 year on the streets, it's second nature now.(FG3 P2)

Homeless people in hostels who were visited by doctors sometimes had better access to services.

In the hostel I'm in at the moment, the chap that's dealing with it told me that if I give him numbers or something he'll get the medical card in a week.(FG1 P7)

I don't have a card but I'm covered by the hostel cover, the one card does the whole hostel. I don't have me own card that's just for emergencies... I haven't went about it.(FG1 P4)

Another obstacle was the renewal process. Some participants admitted that some parts of the form were difficult to fill in or that they

Haven't got round to sending it back. (FG1 P8)

Mine is out of date since last December.. Now it's to get renewed .. I've to get the form. (FG2 P8)

I've sent out my form I had it stamped everything done with it, whatever I was to get done with it, I've sent it out six months ago.. Still waiting. (FG2 P4)

I just put in for a medical card and I got a doctor to stamp it and I'm just waiting to get word. I sent it all back in. (Fg1 P3)

A recent study identified the system of renewing medical cards obstructive to healthcare access for vulnerable people with the reason for withdrawal of medical cards by the health authority in 90% was 'forms not returned'. The study showed that 60% of those sampled had not received review forms and those without an address could were not in a position to (O'Carroll and O'Reilly 2008c)

Where's the care in *health* care?

In many of the experiences recounted it was evident that 'care' was missing. However it was evident that experiences were mixed and some care professionals made their patients feel cared for. However there were examples of 'lack of care' as shown through staff attitudes throughout the services, sometimes resulting in aggressive responses from the participants. Participants spoke positively about individual health care staff who showed real concern and respect.

> *I've a doctor and she really is concerned about me medical problems, but there are doctors that don't give a shit. (FG2 P1)*

> *I have me own GP, I've me medical card, I've me family doctor for me kids. It's hard to get doctors sometimes, but now I've got one out in (names areas) and he's brilliant and he's giving me a 3 month trial and that.. To see if everything is going well. (FG3 P3)*

Another gave an example from the drug treatment clinic.

> *I had to pick up for this fella he got sick in the clinic one day and he had the virus. The GA's were running away and goin ..."well I'm not pickin' it up, I'm not pickin' it up", and I said, "put gloves on ye and pick it up it is your job, the young fella is too ill, he's too sick", so WE went and we helped him. His OWN, people helped him. But some other GA, went out to the door and said to me "no way was I pickin' it up". So I said, "come here it could be him, it could be me, it could be someone else... (FG 2 P5)*

There were varying opinions about drug clinic staff member attitudes towards them however most felt that staff did not 'care' about them. One woman did acknowledge however that there was one member of staff who did care and without her she'd be lost:

I find the nurse has a little bit of time for you, but the rest.. (FG2 P1)

If I was worried or anything I'd go to the nurse. The doctor just sits back "ah no you're alright", (nurse) would take blood off me and she'd send it away ...to reassure me. Cause I've an awful lot of things going on, so... she's alright.(FG 3 P2)

But there's a lot of discrimination in the clinic anyway, and there are some good people there too ye know. (FG1 P2)

What should be Done?

Participants were asked what advice they would give to health services managers. Recommendations mainly revolved around two themes; the desire to being treated 'the same' as everyone else and the view that methadone was 'not the answer'.

Treat every patient the same

Services should be less discriminating.(FG1 P2)

Treat every patient the same, like don't treat some rich person next to me any different then you would me. Treat each person the same don't discriminate against drug addicts. We're people too; we feel it when we're put down by doctors and hospitals.(FG3 P2)

Treat us all with a bit of respect we are all human beings we're all equal, we're not asking for red carpets or anything like that.(FG3 P5)

To try and integrate us into the main society. (FG1 P8)

Treat us all with a bit of respect we are all human beings we're all equal, we're not asking for red carpets or anything like that. (FG2 P9)

Participants felt that the current methadone maintenance was not addressing their needs. They expressed the desire to be free from drugs and seemed less than satisfied to continue on methadone without a long-term plan.

Methadone is not the answer

> *I think they need to stop thinking that throwing people into clinics and putting them on 'phy' is the answer to the problem...And leavin' them there. (FG2 P6)*

> *Not just put them on 'phy' and leave them there d'you know what I mean, help them like. Instead of just sayin "right they have their 'phy' they're not going to be going out robbing for gear or stuff like that. (FG 2 P2)*

> *There's no effort in treatment .. every one is the same across the board... The maintenance and that's it... "keep them on their 'phy' they'll be happy, there will be no robbing". But people don't want to stay on 'phy' for the rest of their lives. They need the resources for when people come down from their methadone so that there's something there for them. (FG3 P8)*

> *Are we to come hobbling in here to get methadone when we're 65'? (FG2 P9)*

Step 2: Priorities for follow up action

Four months after the focus group meetings a feedback session was held with participants to validate the main findings. Thirteen of the original participants attended. Participants agreed with the findings and the following is a summary:

- Participants want to be treated like everyone else and not discriminated against on the basis of drug use or associated health problems.
- Major problems with services were attitudes of staff, lack of confidentiality and inadequate treatment of the person as a whole. Respect was shown by some services and participants acknowledged this (e.g. Merchants Quay).

- The access to free health care through the provision of medical cards seems to be hampered by the reluctance of GPs to take on drug users, the difficult process in applying and keeping card updated and the lack of addresses for homeless people.
- Participants felt that the current methadone maintenance was not addressing their needs. They expressed the desire to be free from drugs and seemed less than satisfied to continue on methadone without a long-term plan.

We asked participants to prioritise the health service problems they had raised, for follow up action. Issues were put up on flip charts and participants given three stickers to prioritise the three most important for follow up action. There was a clear majority of participants who would like to see a change in the way the Mater hospital treated drug users. Discrimination, and the desire to be seen as 'normal' and treated like everyone else was a strong recurrent theme across experiences.

Participants were then asked to rank current services in terms of better and worse. Clearly there was no consensus on some services e.g. treatment clinic and dentists were dependant on individual experiences. In general most ranked GP services towards the bottom and there was consensus around perceptions that the Mater should be ranked at the bottom.

Ranking exercise at focus feedback session.

The three partners committed to:

- Engage decision makers and lobby for change
- Raise awareness where necessary through the media
- Encourage more GPs to treat this patient group in their communities
- Feedback results of these actions to the drug using community
- Monitor actions and outcomes

Step 3: Bringing 'voice' to service providers

Our (UISCE PPR and Mountjoy Practice) aim was now to bring the findings of the focus groups to the health system so that their drug users' views could influence service provision. Between the three organisations a list of service providers who were sensitive to drug service user

needs was compiled. We called these 'friendly insiders'. We produced a draft report of the findings of the participative research and sent it to these people inviting them to a consultation to discuss how to address problems identified.

Consultation with Key Stakeholder Service Providers

This consultation was held in Merchant's Quay Ireland and attended by representatives from Merchants Quay, the Health Service Executive, St James' Hospital, the Drug Misuse Research Division of the Health Research Board, AOM Addiction Services, the North Inner City Partnership, UISCE, PPR, a Pharmacist, GP's and a dentist with experience in treating drug users (O'Reilly, Reaper, and Redmond 2005).

This was a constructive meeting where suggestions for possible solutions were made (O'Reilly et al 2005:p27). Participants invited to this meeting were known personally by individuals in one of the three collaborating organisations (MFP, UISCE, PPR). The tone was set prior to the meeting in a letter which was sent informing invitees that their advice was being sought, 'on how to take the critical issues raised in these group discussions forward and where appropriate on how to facilitate changes in services'.

Notably the two services identified and criticised in the report were the Mater Hospital and City Clinic. Though invited, neither was represented at the meeting. There were also few frontline workers from addiction services or from General Practice (apart from the staff of the Mountjoy Family Practice).Those who were present (community pharmacist and clinic manager) were particularly strong in stating what they called 'the reality' of working with a sizable client group who have an opiate addiction was fraught with difficulties.

Some service providers were not prepared to accept the views of the services we were presenting as valid. After the consultation the HRB Drug research division carried an article in Drugnet describing the meeting as providing "a useful opportunity to discuss the findings of the report and identify practical steps to address the issues identified"(Connolly 2005). The meeting resulted in a table of issues raised, possible solutions, and the body responsible for follow up action (O'Reilly et al 2005: p27). This became the plan of action for 'next steps' some of which included dissemination of findings to the relevant services (presented below).

City Clinic Consultation

The presentation to the staff at the drug treatment clinic 'City Clinic' was far less positive. We had been invited at short notice to present to the clinic, which was chaired by the GP, and attended by about 20 people (General Attendants (GAs), counsellors, nurses, and one consultant psychiatrist).

We had prepared a short presentation focused on issues relating to the drugs treatment clinics. ER and RMA (UISCE Staff) presented most of the finding. My field notes reflect the mood:

> As ER and RMA present their power point slides there are some disapproving grunts and negative facial expressions. I can see this have an effect on the presenters, there tone becomes almost apologetic. RMA starts giving his own understanding view after presenting a finding... he presents the finding 'some doctors in the clinic would treat general conditions while others did not', he goes on to say " this is understandable but they really should have their own GP outside the clinic.

When the floor was opened for comment there was a mix of responses. The consultant psychiatrist was "surprised by some of it" one thing however that had struck home was the need for sound proofing in the counselling room upstairs. He said he was not aware that you could hear from the outside;

> *"You see I'm always inside the room never outside the room" (Psychiatrist, City Clinic)*

On confidentiality, one of the staff said that the clinic has a clear service users' sheet explaining all about confidentiality and "exactly what happens with what information". She said it had been "language proofed and everything" so that it was clear. However service users were not involved in drawing it up.

Another staff member (a counsellor) said he did "understand there is an issue around confidentiality", and that there was "nothing new in what we presented" that most of it was "relevant" and "true", he did not agree with the lack of treatment options.

The psychiatrist pointed out that things had improved greatly in 20 years, that now people had a service and could complain. He said that his "was to involve the user" that everyone should experience a positive induction. He said there were some misconceptions but that these were the result of a "failure to communicate".

The addiction services GP coordinator (Health Board employee) who was chairing the meeting felt that the presentation "lacked balance". He felt the views presented "did not reflect "the views of those who silently come and go" and who were not "the more vocal clients known to UISCE".

Someone else commented that the findings were "very negative to GAs". There was some discussion about the example that ER gave about the vomit not being cleaned up by staff. GAs seemed shocked by this example and said this would never happen.

In the partners meeting afterwards we expressed our surprise at the reaction we got. Though we congratulated one another, we were deflated. We had been put down and rejected. We noted that the Clinic had never conducted an evaluation of their own or a satisfaction survey. AOC said that he would evaluate his own service from his service users perspective and "lead by example".

The Mater Hospital

We had sent the report 'We're People too' to the Mater and a meeting was arranged. We were expecting the CEO, the Infectious Disease Consultant, and the Patient Services Manager. We were met by the Infectious Disease Consultant only, who had read the report. He invited us to speak initially, and listened to the issues we raised that had come from the focus groups discussions in relation to the Mater hospital. Although both the UISCE workers and the Consultant have extensive experience in this area the Consultant did not appear to consider that the UISCE workers opinions were relevant, relative to his own. I noted at the time:

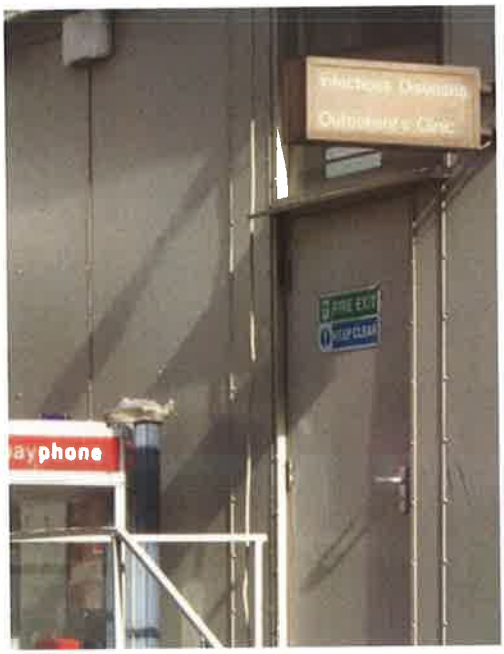
> 'He went through the different "spectrums" of people on drugs from those that managed to come off methadone without replacing it with drink or other drugs to those relatively stable on methadone to those who were chaotic who were active users with a mix of addictions and were out of control'.

ER interjected a couple of times giving her own opinion;

"Ye but they're saying they don't want to be left on methadone", she said.

" Well this was one of the fears from the beginning", (the Consultant proceeded, "that the introduction of the protocol would mean that people would simply be parked" He said that the way he understood it people were selectively identified within the system and slowly withdrawn from maintenance.

The Consultant was generous with his time and his views and courteous, however he rejected the validity of our findings because they were based on focus groups with 25 people and not more scientific methods. He said that he "had hundreds of satisfied customers". He did not rate UISCEs position as a Drug Users forum and questioned their representation saying there were at least 10,000 and asking " how many of these do you represent?"



The 'infectious disease sign outside the Mater hospital

A specific issue which had come up in the focus groups was the 'Infectious Disease' sign outside the clinic where many of them attended. The Consultant did not agree that his patients had a problem with this. Though, he said the sign did not work very well as a 'sign' the Consultant would not consider removing or replacing it with something more ambiguous. He had however given the matter consideration and had consulted with his staff on this issue. Nevertheless even on this seemingly small change, we and the voice's we were endeavouring to represent drew a blank:

I asked whether there was there anything that they could do on the labelling and signage issues.

Regarding the sign that says "Infectious disease" (the Consultant) gave a history of similar issues with signage of sensitive diseases. For example 'the Sexually transmitted Disease clinic or STD clinic was once called the 'VD clinic' so that it wouldn't be that

obvious as to was it stood for ...and then that became sensitive. At one point there was no sign for the STD clinic but it was the only clinic open after 5pm so everyone knew what people wandering around the grounds after 5pm were looking for. He said that James's had gone down that road with the GUIDE clinic[32].

He concluded on this by asserting

" I've spoken to the staff and we are not interested in hiding the stigma. We believe in calling a spade a spade. This is what we do, we treat Infectious disease which also includes Hepatitis Toxoplasmosis and kidney infections"

"So we will not change the sign"

He believed the patient didn't have a problem with it as he often passed them outside having a smoke in groups underneath it where they could be seen by everyone. (field notes Mater meeting).

We had an interesting and courteous exchange with the consultant who had taken two hours to engage with us, he had read the report and consulted with his staff. However he fundamentally rejected our representation of drug users' voice, he defended his service and he was not willing to change anything arising from our presentation.

The matrix below (table 8) categorises the reactions from service providers to the presentation of service users voiced. Areas in which providers agreed with focus group findings included:

- The difficulty for drug users to access GPs.
- Service providers view maintaining service users on methadone in a more positive light than service users do.
- Acknowledgement of labelling.
- Problems with confidentiality.

However there was a tendency to defend the current system and resist change. Needs identified by some of the service providers attending the consultations were 'a paradigm shift from a medical to social model', equity of services, dialogue and communication and further development of the quality of the inpatient service.

[32] GUIDE Clinic (Genito-Urinary Medicine and Infectious Diseases) was known only by its acronym.

Table 8 Reactions to 'drug users' views' by service provider

Themes	Service provider key stakeholders (friendly insiders) 28th June 2005	Meeting with Drug Treatment Centre Staff 11th October 05	Meeting with Mater Matter 18th October 2005
Source	Derived from summary of consultation prepared by me sent to participants for agreement.[33]	Taken from my notes during and directly after the meeting and, written feedback from Drug treatment centre and follow up clarifications[34]	Taken from my notes taken during and directly after the meeting
Statements about the process	The report represents Drug Users Views. It is a stage in a process to improve services for this client group and will allow their views be taken into account in the planning and implementation of services. Participants welcomed the initiative taken to assess the views of drug users on services and felt it was important that the voice of the drug user was heard in the system Providers were eager to work together to solve problems raised.	*Psychiatrist pointed out that things had 'come on' in 20 years that now people had a service and could complain. He said that his "vision was to involve the user" that everyone should experience a positive induction. The staff felt that 'the Presentation did not acknowledge the limitations of the study' and it was 'felt that it was delivered in a negative manner'. The staff said that the 'Context given was generally unsatisfactory, positive aspects of the service acknowledged in document but not in presentation'.	*No specific comments made: However UISCE's representation of drug users was questioned.* *Also personnel for patient services and the CEO did not arrive though they were invited*

[33] O'Reilly F, Reaper E, Redmond T, We're People Too. Views of drug users on health services. UISCE, PPR and MJSFP Dublin June 2005 p28.

[34] We received two pages of feed-back. The subcommittee who put the feed back together consisted of two GPs one counsellor one midwife a pharmacist and a general assistant.

Statements concurring with findings	There is a general difficulty in getting additional GP's involved in the methadone protocol Providers see continuation on methadone maintenance in a more positive light than users do.	The team acknowledge that there are difficulties in obtaining GP's. All clients are advised to apply for medical cards. Confidentiality: 'Team acknowledge that there are physical limitations to the building in relation to confidentiality (top landing/pharmacy area)' (The senior GA is privi to information and other GA s called into part of the discussion which concerns them)	On the labelling of charts with stickers : He said that he disagreed with that rule and explained that it was because the microbiology department wanted the specimens marked with stickers.
Challenging validity	There were some comments that the report focused mainly on negative views and did not represent the many clients who are happy with services and treatment. It was stressed that the issues raised were based on client's perception. The provider group felt that findings may not be accurate reflections of reality but nevertheless were issues that needed to be addressed so that perceptions change.	GP said that the presentation lacked balance, he said that the views did not reflect the views of those who silently come and go and not the more vocal that may be known to UISCE. Question around the selection process of the participants Staff said the assessment 'needs to be more representative of clients on clinic'. The staff 'take on board the criticisms in the report but note that participants for study were recruited by UISCE. This is not acknowledged as a potential bias'.	He rejected the validity of the focus groups because it was based on 25 people and he had hundreds of "satisfied customers". He said that this assessment was not scientific.
Defending the current service	There are issues of security/confidentiality for services which necessitate implementation of rules and regulations for clients. A wide range of comprehensive addiction services exist. However these are sometimes challenged by limited resources and infrastructure.	'This is a drug treatment centre and not a Primary Care unit' 'All clinical staff members do their best to maintain confidentiality within the guidelines of their professional bodies and HSE Addiction Service policy guidelines.'	He says that the OPD was now reasonable they had doubled up on space and had more medical personnel. He goes on to say that the Consultant Psychiatrist at City Clinic offers a good liaison service for the treatment centres. He said that whatever about perceived / actual problem in the hospital they were less likely to happen on Bernard's. (Bernard's is the inpatient facility for complicated infectious diseases. Much of the ward is therefore dedicated to drug addicts with complicated infections).
Disputing specific findings		*There was some discussion about the example that ER gave about the vomit not being cleaned up so one of the other clients cleaned it up. GAs said that this would never happen.	On how drug users are treated at the Mater "In principle every is treated in turn based on medical criteria".

		On staff attitude: Staff 'felt that in the document that there was misinterpretation of professional behaviour. Information is shared by members of the clinical team as is appropriate and necessary.' (further clarification of this point revealed that the senior GA is privy to information and other GA s called into part of the discussion which concerns them) Every client who attends the clinic is offered counselling but a high number do no avail of the service	On Signage: He believed the customer didn't have a problem with it as he often passed them outside having a smoke in groups underneath it where they could be seen by everyone.
Acknowledging problems	Due to difficulties within central services, Primary Care services (e.g. pharmacies) are taking on unstable patients that were not envisioned in original protocol. There was a high level of people without medical cards among this vulnerable group.	There is no local complaints officer. The centre had been piloting a local system where two members of staffs were identified as complaints officers. However they felt that this was compromising their relationships with members of staff against whom they may have to bring complaints.	"The Mater has the most stressed out A&E in the country". He acknowledges that there may have been differential treatment in the past; he said that now "50- 70% of staff will not take that attitude". He explains that though he is the Infectious diseases Consultant that never the less every 13th night he was responsible for everything that means any one coming in to casualty. The proposed increase from to 1 night in 6 which would invariably have an impact on the use of inpatient facilities for drug users with complicated infections. He spoke about conditions being terrible for everyone not just drug addicts
Needs	A paradigm shift from medical to social model is necessary. Equity of services needs to be embraced.	The conclusion was from psychiatrist there was a need for dialogue and communication	He felt that the quality of the inpatient service needed to be further developed.

Step 4: Monitor Influence and Outcome

Table 9 (page 226) shows limited policy change attributable to the action research project but only one practice change in one clinic. However it does not contain the complete picture in terms of outcomes. Measurement of the influence of this attempt to bring drug users views into the frame does not include indirect outcomes. The report penetrated all levels of the services and people at the 'top' were aware of it and its content. Other research was stimulated as a result (A study of the removal of patients from GP lists (Clarke, Whitford, and O'Reilly 2007), and a study of User involvement in Primary Care). The process of the action research project and the resultant publication helped raise UISCE'S profile and access to Primary Care service providers. It also influenced the development of the detoxification option and the review of the medical card renewal systems (O'Carroll and O'Reilly 2008).

Nevertheless the table of outcomes (table 10) for example indicates minimal service practice and policy changes which were monitored for two years following the focus groups. The changes which had been agreed to with the health authority Addiction services manager which would lift structural barriers to medical card access (i.e. assigning GPs and fast tracking cards) were not implemented as the Clinic was not putting requests through for this. Eventually a CWO working with another clinic established the fast tracking system which was working well until the medical card sections in the new HSE were centralised and it no longer was possible.

- City Clinic assigned key workers to all service users.
- Finding that people were not content to continue indefinitely on methadone, contributed to (among other influences), the addition of the 5th pillar – Rehabilitation to the National drug strategy[35].

In terms on increasing the access to methadone in Primary Care there was no progress at the end of follow up. As can be seen from the last sections there are barriers to this in the community. The same numbers of GPs in the NICP area were involved in 2006 as in 2004. Also

[35] Mid term Review of the National Drugs Strategy 2001-2008.Department of Community, Rural and Gaeltact Affairs. Report to the Steering Group, March 2005. This review commenced in April 2004 and in October 2004 there were numerous consultative forums held around the country. The findings of the focus groups were at this stage being disseminated even before the final report document was written up. ER presented to community groups and members of the National Drug Strategy Team. And as she says "shouted from the mountain tops" that users were fed up with methadone

the NICP which we had planned to utilise to create awareness and explore barriers among GPs, ceased to exist (chapter 9).

After a two year period the three collaborating organisations handed the continued follow up of the outstanding issues over Progression Routes Initiative (a collaboration between community and statutory agencies involved in working with people with an opiate addiction). Progression Routes Initiative (PRI) enrolled AOC onto their management committee and continued efforts to progress issues raised on an on-going basis. One success targeted the finding that 'methadone was not the answer' and that drug users' did not want to be on maintenance indefinitely. The PRI developed an 'Outpatient Detoxification Protocol' from Methadone and Benzodiazepines which was successfully piloted in 2007 and 2008 (PRI 2007). This protocol presented an alternative to being kept on methadone maintenance indefinitely. The co-ordinator of progression routes acknowledged the influence of the 'We're people too' report in the prompting the protocol development, which she said "provided background for the initial research into the issues and solutions". (Co-Ordinator Progression Routes Initiative 2008)

In 2006 I undertook a study of the Mountjoy St. Practice drugs service users' views (see published paper at appendix VIII). I also explored how service users felt about their own involvement in decisions about their treatment and care. This confirmed findings that people did not wish to be on methadone indefinitely. Service users experienced opportunities for involvement in dialogue with their GP and having a say in the methadone dose but did not have an opportunity to engage in more structured or contractual forms of involvement in treatment such as written care plans. Those who had stabilised had less of an opportunity for involvement (O'Reilly et al. 2011)

As a result of the study a half day consultation was held in a hotel with service users and practice staff. I presented findings and hosted a lively discussion where service users were determined to have their say and providers obliged to listen. The outcome of the consultation was that two service user representatives were nominated and the Practice committed to the following;

- More Dialogue
- The establishment of a complaints mechanism

- The nurse attending training on the methadone protocol so that she could be involved in patient care and so that the recommendation for providing varied treatment options, in line with patient's own goals, could be achieved
- Changing the system of service delivery to enable clients to be treated in the same manner as 'any other' practice patient. (In practice this meant giving patients the option to be treated upstairs in the regular GP surgery and not downstairs in the basement where the HSE operated a drugs clinic with stricter rules and regulations)

Changes made in the practice were very slow to take effect. Even though AOC saw the need for the changes and that he now had the 'power' to make them, progress was slowed by the virtue of the fact it was a very busy practice. Eventually, all of the changes were made and implemented. The most significant change, which went beyond original commitment, was that all the drug services users who had been treated separate from other practice patients in consultation rooms in the basement were moved 'upstairs' and were treated in the main practice "like everyone else".

Table 9: Policy and practice changes on issues raised

Issue raised	Action	Outcome	Policy/practice change
Barriers to Medical Card access GPs Gate Keepers of Medical Cards Difficult process to understand	Area Manager of addiction services and Project coordinator met with Medical Cards section administrators areas 6 7 8.	Medical card applications from addiction services and homeless services to be fast tracked Clients to be assigned GP without '3 refusals'	Practice& reverted Policy & reverted
Hospitals Poor perception of treatment by acute hospitals particularly Mater	UISCE PPR and Mountjoy Street practice met with Infectious disease consultant at the Mater Hospital. (CEO and patient services did not attend)	Did not take account of our findings	No
GPs Reluctance to be involved in methadone protocol	Issue was raised with addiction services and Social Inclusion	No increase in numbers of GPs in the NIC area involved in the protocol.	No
Methadone Perception that it's not the answer	Presentation made to treatment centre by UISCE PPR and MJSFP Awareness raising at consultative forums through UISCE and LDTF Dissemination of Report We're People Too	City Clinic initiating a system of ensuring all clients have key worker Mid-term review establishes the 5th pillar (Rehabilitation) Progression Routes pilot out-patient Detox	Practice Policy (contributed) Practice
Confidentiality Perception that all staff knew 'their' business. Counselling rooms not sound proofed	Discussed within addiction service and presentation of findings made to Treatment service City Clinic to sound proof counselling room	No change Informed that all patients receive sheet saying what happens their information (since 2003) Not done	No No
Pharmacies Unreasonable / unrealistic contracts devised by pharmacies	UISCE reviewed proposed contracts prepared by Institute Pharmaceutical Services and gave feed back	Contract still in use	No
Dental Care Poor access to Dental care	Dissemination of this report among HSE and DoH	Nothing done	No

Discussion: Space and power

This account of drug users' interaction with health services shows the chasm between the policy rhetoric about involvement in decision making and the real experience and perceptions of those using the services. The action research project opened a new dynamic transient space which combined varied perspectives and talents supported by access to resources. This space falls under Cornwall's 'fleeting formations' category which are aimed at 'opening up deliberation over policies or service delivery priorities' rather than decision making. She says these spaces capture attention and capture commitment for action (Cornwall 2002).

Cornwall agrees that spaces arising organically rather than by invitation may offer ways of ensuring more marginalised groups influence governance (Cornwall 2002;Cornwall 2004). Efforts for Local Drug Task Forces to maintain drug user representation was in fact only successful in the case of the North Inner City. Rather than recognising the likely re-creation within these spaces, of power differentials which exist in society, I have heard the 'chaotic' lifestyle of the drug user blamed for their lack of ability to participate in such invited spaces. The UISCE representatives who did engage in invited spaces were in fact not typical of the group they represented in that they were articulate, confident and from middle class backgrounds. This is no co-incidence. The lack of representation of the typical drug user from deprived areas in invited spaces such as drug task forces is because those spaces are imbued with power differentials so as to exclude the representation they invite.

The development of treatment services in response to the 'heroin crisis' sees top down covertly developed treatment system based on a medical understanding of heroin dependence (Butler 2002). Control and regulation are highly valued in this system; control of medical practice as well as patient behaviour are determined rule and regulation (Department of Health and Children 1998;Government of Ireland 1998). Power differentials are set from the start in a system where clients must provide urine samples under 'supervision' weekly (i.e. watched urinating by people employed for this purpose- GAs) and watched drink their medicine to ensure they are not selling it (daily for some, weekly for others). Interestingly these defining and controlling aspects of services were not complained about in the focus groups. Nor do services regularly hear complaints from service users. Research suggests that this is because that drug and alcohol service users often perceive themselves as undeserving and have low expectations (Etheridgeet al. 1995;Maddenet al. 2008).

The lack of conflict or complaint however that Lukes (1974) suggests may also indicate 'an acceptance of the role in the order of thing, because they can see or imagine no alternative to it, or because they see it as natural and unchangeable, or because they see it as divinely ordained or beneficial'. The study I conducted with the Mountjoy Family Practice service users suggests (according to quantitative analysis of closed questions) that they saw controls as beneficial. However open answers suggested that many were uncomfortable about some of the practices but they had gotten 'used to it'. It had become natural and in any case was unchangeable (2011). Lukes' says that lack of grievance does not equate to consensus'. The Psychiatrist's comment that the services had 'come on' in 20 years and now clients could complain, suggests to that he saw this as an improvement. Others however interpreted lack of complaint as indication that things were ok. The feedback session for the Mountjoy Street Practice saw a couple of irate service users confront the Practice doctors about personal grievances in public. Though this was difficult for staff it was an indication of a more equal power relationship. There was no fear of repercussions. There was no suppression of voice.

Bergschmidt (2004) argues that the methadone substitution programme in Germany is a technology of bio power, disciplining, normalising and controlling those constructed as dangerous. Because heroin addiction is constructed as a medical discourse, she says, it is presumed that programme participants must be observed controlled and disciplined. This is not unlike the Irish System. Production of individuals who are disciplined and controlled reduces risk of dangerous crowds, wandering vagabonds and epidemic diseases (Foucault 1984). The epidemic disease targeted for control with the introduction of the Methadone Protocol was of course HIV and AIDS.

Foucault's 'dividing practices' saw the drug users were divided from society physically (housing was their biggest priority and yet unmet need) and socially (Rainbow 1984). Through the 'science' of methadone they were segregated further, in clinics for the treatment of heroin dependence. They themselves were acutely aware of the 'dividing practices', though they spoke about them differently. They even sometimes saw them in places where there may not have been an intention to segregate or as Foucault says 'make legible'. The example the focus group participant gave about being fast tracked through casualty because he was a drug user and CF's folktale about drug users being scarred with an X , may have been misread signs. They

nevertheless show how cut off from 'normal' society the people with a stigmatising opiate addiction felt.

Procedures using power and knowledge also shape identity through "dividing practices". Many of the drug users spoke as if they were totally accepting these identities;
"I was 'an anti-social behaviour'," one woman identified herself as the 'title name' of the order which resulted in her exclusion from her home and her community.
Another says "they know what you are." She did not refute the label she was given. She 'knew' what she was; an 'addict', a 'junkie' or at best a 'drug user'. The label was not the point of grievance, others knowledge of it was.

Though the action research gave opportunity for grievances to be aired in a safe environment among peers, the internalisation of negative identities has contributed to an acceptance in the order of things. The desire for normalization, though strong, is unlikely to be realised without a radical change in the order of things.

> *Right we're on drugs, we didn't set out to say right we're going to end up on drugs. Unfortunately we got strung out.. We're on methadone , we're paying for it. I know there's a lot of people payin' for it because we're on drugs.. We done bad and whatever but treat us equally"*

Cornwall says of the type of temporary space we created:

> It is the conditional, transitional fleeting nature of these kind of spaces that make them sites of radical possibility as well as for the maintenance of the status quo (2002).

Despite the commitments that were made, the services went back to maintaining the status quo. Ambitions such as user involvement in decision-making, appear idealistic alongside their requests to be treated with respect, and without discrimination.

> *"Treat each person the same don't discriminate against drug addicts.*
> *We're people too; we feel it when we're put down by doctors and hospitals"*

More than a grain of truth

Doctors did not go out to intentionally to mark drug users with an 'X' for easy identification by other health professionals. However this folktale persisted. A failure of communication and shared understanding allowed both service provider and user to meet, yet their experience of the event was extremely different. Similarly, drug users' views of services presented above did not 'ring true' to many of the service providers who were presented with them. This voice was alien to them, and so, they discounted it. Services may not have intentionally discriminated against drug users or intentionally show a lack of care. Nor did they intend to treat service users like second class citizens' yet this was the perceived and expressed experience of many. Fetterman (1998 p 61) points out that it is the perception of reality that is more important, than the objective reality, in shaping behaviour. Indeed if the Health Strategy's (2001) aim to put the patient at the centre of the health system is to be realised then the patients' perception becomes central.

Chapter 9 A Primary Care service providers' partnership

> Levering open arena once closed off to citizen voice or public scrutiny and drawing on alternative visions of democracy, these moves have helped to widen political space for citizens to play more of a part in making and shaping the decisions that affect their lives (Brock, Cornwall, and Gaventa 2001)

As we have seen from chapter 6, if Primary Care definition includes interventions to tackle the social determinants of health, then the community were involved. However, they were not involved in decision making about service planning and development. Many suggest that involvement at this critical stage is necessary for meaningful involvement (Coulter and Ellins 2006;Jordanet al. 1998b;Pickard and Smith 2001). Action 19 of the Primary Care Strategy (2001) commits to strengthening community involvement through encouraging and facilitating the involvement of local community and voluntary groups in the planning and delivery of Primary Care services.

The NICP was a space where services were planned and developed. The NICP had agreed to participate in this research from the design phase and was seen as the forum to develop links between Primary Care provision and community. This space was occupied by the key stakeholders involved in Primary Care provision, both GPs and the health authority personnel. Importantly from my perspective it was a space in which there was an associated budget to support decision making on Primary Care services. There was no community representation within the partnership or community influence on the partnership agenda. This was something the GP initiators of this project were interested in developing. I was interested in uncovering the kinds of decision that were made in this space, determining how they were made, and which factors influenced decisions. I was interested in what sorts of power relations existed in this space. I was interested in observing and describing what efforts were made to 'levering open' this arena to facilitate a community voice. Cornwall (2004) states that situated ethnographic and historical research is needed if the transformative possibilities of participation are to be better understood. Spaces exist in a dynamic relationship to one another are constantly opening and closed through struggles for legitimacy and resistance, co-option and transformation (Gaventa 2004;Hayward 1998). During my engagement in the NICP

space, decision making in other arenas (the Health Services Reform Programme, and the development of the 'Out of Hours' service) impacted the NICP space to the extent that, coupled with power and cultural differentials, as well as 'the mobilisation of bias', the space closed.

This chapter is divided into four parts. The first describes the NICP; its evolution, purpose and activities as well as its culture. The second part describes the NICP's efforts to involve community. Part three traces the effective 'closure' of the NICP space and the fourth traces the development of a service by the same partner mix in a closed space. Finally, findings are discussed in terms of space, power and interests.

Development of the NICP: Bringing GPs in from the cold

The NICP was established in 1997 as a consequence of the successful development of the South Inner City of Dublin Partnership in Primary Care (SICP) (NICP 2004b). The impetus for the development of the SICP was the closure of community hospitals in south Dublin City in the late nineties. The hospital's closure was part of in an attempt to re-organise hospital services in Dublin. Prior to this attempt, acute hospitals in Ireland had evolved without a national plan, often developing in response to perceived local needs (DOHC and Hanly 2003) As part of the reorganisation, the Meath Hospital in the south inner city of Dublin had to close. This rationalisation of acute services had been recommended as far back as the 'Fitzgerald Report' in 1968 (The Consultative Council 1968). There was strong local resistance to the closure of the local hospital as the Dáil debates at the time reflect (Dáil debates 05/03/98)

Nevertheless and despite adverse public opinion the hospitals were closed and were replaced by the new Tallaght hospital opened in south county Dublin. This reorganisation presented a potential gap in service provision and therefore presented an opportunity to reorganise Primary Care in the area. As a consequence, the Primary Care needs in the area were examined and the old Meath hospital was identified as a possible site for the development of a Primary Care Centre.

MW[36], a Health Board manager at the time saw this as an opportunity engage with GPs and "foster a better relationship" as well as develop community based service provision.

> *"It started in the South Inner City with the closure of the Meath. There was really huge angst at that time with the hospitals moving out, angst with the GPs who would have thought themselves helpless in the area. There was huge angst politically and with the Department, and nobody knew how the thing might be fixed. At that stage I had moved into community service and I set about meeting with the GPs in the South Inner City." (Interview with MW, Assistant CEO, Northern Area Health Board)*

ML also recognised the poor relationship that existed between the Health Boards and the GPs supported by the Department of Health (DoH). BS[37] agreed with this analysis saying that the DoH;

> *"Never really built up a relationship of trust between 'them' and 'us' which has sadly prevailed to this day." (Interview BS Prof General Practice, RCSI)*

Another health authority manager recalled that GPs were very isolated in the community.

> *I can understand the reasons why it was done [establishment of the NICP], because GPs were out there, they really were out there. It won't be forgotten about, and you had community services doing their own thing here, so it was trying to bridge that gap (Interview with health authority Manager).*

MW approached GPs on the north side of Dublin to establish a similar structure as the SICP however there was an important difference. GPs had survived hospital closure on the north side of the city ten years earlier without assistance from the Health Board who, as MW put it had not taken the opportunity to bring the north side GPs "into the fold". When he started engaging with the GPs to explore the potential of establishing a partnership, he was greeted with suspicion;

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[36] Michael Walsh was the assistant CEO of the Northern Area Health Board July 2005.

[37] Prof. Bill Shannon. Professor of General Practice RCSI (May 2006)

'Our GPs in the north Inner city wondered what we were about, because they were all very happy 'thank you', and didn't want to know about us.. So, we thought we would go in and shake hands and everything was going to roll, but it wasn't like that at all [laughter] and we actually found that people were looking at us and being quite suspicious. But eventually, we did get them to feel well, it's worthwhile starting to talk the talk, and there were four GPs nominated then.' (Interview with MW)

A GP on the management team described how the Health Board went about setting up the Partnership and noted that it was a positive departure from the norm.

"The Health Board, it actually set out to be democratic this time.... The Health Authorities had very little interest in GPs in the past, and it was only with the onset of guys like Mick Walsh in the Health Board who was interested in GPs and sought out their opinions that this project [the North Inner City Partnership] developed."(Interview with Management Team GP)

Purpose and actions

The stated aim of the North inner City Partnership in Primary Care was to

> Improve people's health by fostering and developing an integrated approach to patient care involving family doctors, hospital professional's, Health Board professionals and the respective managers and support personnel as well as other service providers. (NICP 2004a)

The objectives of the Partnership were to 'augment existing services and develop new services, to co-operate across primary, community and hospital sectors[38]' (NICP 2004a).

The management team to oversee the development of the NICP comprised, the assistant Chief Executive, NAHB (Chair);four GPs (nominated by members; Health Board GP Unit doctor; General managers from Community Care Area (CCA) 6& 7[39]; Directors of Nursing CCA 6&7;

[38] Primary Care here meant GP services and community meant Health board staff working in the community

[39] General Managers represent a broad range of multi-disciplinary staff e.g. clerical, administrative

Director or Primary, Palliative and Cancer Services; A Senior Medical Officer and the NICP Project Manager.

In 2004 there were 49 GPs working in the 35 ED comprising the NICP area who were members of the Partnership. This rose to 56 within 30 practices serving a population of 109,000 approx. The original boundary was defined as the catchment of the Mater Hospital. In 2003 boundaries were expanded to include GP members' patients outside the original boundaries. Apart from the Project Manager (PM) and her secretary by 2004, 5 staff had been employed to work with the 56 GP member's practices these included; a physiotherapist, 2 nurses, a social worker for elderly and a psychologist. There had been plans to employ other health professionals (Dietician, Occupational Therapist and Speech and Language Therapist) however these did not materialise.

These staff gave GPs direct access for their patients to physiotherapy, assessments of older people, 24 hr blood pressure monitoring for older people social work services and psychological services. Other services were established also including a courier service to and from the relevant institutions for medical specimens, post, and vaccines .The table below (table 10) presents the NICP projects in existence in 2004 at the start of my field work. The 2004 Annual report reports high usage of NICP staff services by GP as summarised below;

> Nurses had received 244 referrals from GPs for assessment for older people and had conducted 516 24 hour ambulatory BP monitoring. The Physiotherapists had received 555 referrals from GPs. There was a 50% increase of GP referrals on the previous year with 150 referrals made to the psychology service. Seventy per cent of Partnership GPs had used the service. There were 151 referrals to the NICP social worker, the majority came from the Partnership nurses with23 from the GPs(NICP annual report 2004).

A key focus was on improving communication between Primary Care service providers in the catchment area and between the GPs and the Hospital. To this end a number of initiatives were undertaken including a newsletter for GPs and Hospital staff, a directory of services and staff working in the community including the names of Public Health Nurses listing the street

names they covered, a directory of mental health services and a map locating GP Practices and Health Services and Hospitals. Several initiatives had been successfully undertaken to improve communication and information flow between the GPs and the Hospital.

Table 10 NICP Projects

Project Name	Deliverables
GP Direct access to diagnostic services (x ray and ultrasound)	GP general x-ray and ultrasound service for patients of NICP GPs
Physician Access line (Pal)	GP direct access to consultants in Mater
Cardiovascular Lifestyle Assessment of Risk Clinics in the Elderly (CLARCE)	Community based clinics (Rathdown road) for older patients with Cardiovascular risk factors
To address parking problems for GPs and nurses in NIC	Parking system for GPs and Nurses who have to make emergency house calls
Female Health Initiative	Women's health clinics to be provided by GPs covered by STCs
Develop /evaluate community involvement in NIC	Conduct research to identify mechanisms and provide understanding on this topic
Computerisation and needs analysis of data collected on patients seen by partnership Nurses	Determine needs of older people. Computerise info collected by partnership nurses
Evaluation of the 24 ABPM Service for patients in NIC	Evaluation of this service
Directory of Service	Update directory
Develop automated d/c letter from A&E and OPD to GP	Develop automated discharge letters
Co-ordinate CPR training for GPs	Basic life support for healthcare Providers Course organised for GPs
Waiting list initiative for Psychology/ counselling service	Provision of group work for people on waiting list
Services for older people	Employ senior OT and Speech and Language Therapist to provide services to older people
Establish Temple street forum	Agree common agenda
Establish Rotunda Forum	Agree common agenda

Success of the NICP

The NICP was seen as a success story by the GPs involved and the original Health Board members who were involved from the start. GPs I spoke to generally felt positive towards the Partnership and the services their practices had 'received' through it. I noted too, that participation at General Meetings was good with 20 to 30 GPs attending. Some GPs I spoke to felt the reason it was successful was due to strong GP representatives on the management team. GPs also recognised the goal of establishing dialogue between the Authority and the GPs. The main achievements according to the GP Chair were that it,

"It created relationships between GPs and other professionals in Primary Care; nurses, social workers, physios and administrative staff. It also established dialogue with secondary care.. mainly the Mater hospital." (Interview with GP Chair)

Protocols were developed at the interface of primary and secondary care and it was in the process of developing similar relationships with paediatric and maternity hospitals.

Another GP member of the NICP:

"Yeah it's provided a lot of scope for us, I think, we can now provide, the likes of blood pressure monitoring service for patients that would have been a huge expense previously. One big area I find is psychological counselling has been tremendous, we've used it quite a lot, and I think there's been a big improvement. ..definitely I feel it has been positive. I did last September an excellent course for personal development, from the point of view of clinical skills, on resuscitation run by the Ambulance and the Eastern Health Board, and it was absolutely fantastic and that was funded by the Health Service Executive. That's one of the best things I've gotten sort of on a personal level"(Interview with GP NICP).

One major success was described by a GP as the directory of services in Primary Care for the whole area.

"It consolidated in one forum all the work done in Primary Care in the North inner city. And put it together in one accessible manual (red service directory). More could have been done if it continued."(Interview with GP NICP)

However there was recognition that only a certain amount could be done within this space;

"So it was a fairly successful. Its remit was never to forge a broad close linked partnership. It was very loose confederation to achieve limited aims, improving the day-to-day activities of GPs" (Interview with GP NICP)

Ways of working

The Partnership operated through a structure of monthly or bi monthly management team meetings, subcommittees for specific tasks and themes, and annual or twice yearly general meetings (called 'study nights' in the early years of the partnership). The Project Manager with one secretary conducted the day to day business, progressing management team and subcommittee agreed actions with the sub committees meeting to progress projects.

GP members identified priorities at the annual meeting or through their representatives on the management committee or they arose out of the management committee meetings. There was no formal mechanism of exchange between GPs on the management committee and the GP members outside the annual meetings. Informal communications between GPs on the management committee and those they represented occurred informally at other meetings and engagements. Management team GPs would sometimes "phone around" GP members to prompt attendance at a specific meeting of importance or to gather a snap shot of views on a particular issue.

The lack of trust at the start of the Partnership influenced behaviours at management teams though this changed over time. Minutes from the early years showed 'nit picking' over wording, and resistance to Health Board suggestions. While resistance to taking services out of hospitals without being funded to do so remained, a level of trust grew , as MW recalls;

> I mean to see somebody who would be looking down every line and all of a sudden you wouldn't even look at your minutes of a meeting, you just went on to whatever the business was, you know, and I suppose that was one part of it.

Accommodating a clash of cultures

GP and the Health Board /HSE personnel come from very different organisational cultures

> The two cultures approach all levels of work differently from decision making, managing conflict and running meetings to the use of language and jargon. (Office of health management)

During the time of my field work there had been personnel changes; new NAHB executive, new GPs on the management team, a new Project Manager and a change of General

Managers. The change in personnel brought a different way of working and even a different way of recording minutes (less detailed). A 'role' organisational culture (often stereotyped as bureaucracy) was evident in the running of the NICP (over the period of my field work) which was done by health authority personnel. In this culture the role of the job description is often more important than the person that fills it. Performance over and above the role is not required and indeed can be considered disruptive (Handy 1981). Role organisations require a stable environment to succeed. Role cultures are slow to see the need to change and slow to change even it the need is seen. Thus when the GP partners disengaged from the partnership the meetings continued for a further seven months. In a changing environment the role culture is likely to forge ahead confident in its ability to shape the future in its own image. This from of culture is successful if there is a monopoly (which in a sense the health authority has) (Handy 1981).

GPs fit better with the task/project/job culture, which though difficult to judge second hand, appears from interviews and minutes more in keeping with how the NICP operated up until 2004. The whole emphasis of the task culture is getting the job done. Influence is based more on expert power than on position or personal power. Task culture is found where speed of reaction is important (Handy 1981). GPs as independent business men and women did not have time to deliberate in meetings for hours and so NICP meetings were held at lunch times and general meetings in the evening.

I noted differences in how meetings were conducted. GP meetings (without Health Board staff), were unstructured and informal and without minutes. health authority run meetings were systematic and structured and always minuted. In fact they had a pattern and rhythm almost stronger than the content.

Ritual and Rhythm

Each meeting started with the 'tea ritual'. This social activity provided the opportunity to chat as people without institutional agenda. Sandwiches, tea and coffee were always provided by the HSE. The sandwiches were ordered and delivered prior to the start of the meeting. Then tea and coffee had to be made or the sandwiches, cups, plates and flasks brought from the kitchen and uncovered. I always helped with this task and as a result built cordial relationships with the secretary the Project Manager and others who would be there for tea. In general it

was the HSE staff who were involved in the pre meeting tea chat which invariably included 'safe topics'; discussion of the sandwiches (nice triangular, assorted, gourmet variety). GPs were generally pressed for time and often missed this pre meeting 'ritual'. The pre meeting tea making and sandwich admiring ritual was important. It repeated itself, it was constant, it could be counted on, it set a tone, and it was safe. There would be no confrontation on the issue of tea and sandwiches. The business of the day was conducted in the tone set: neutral, pleasant, non-confrontational.

On the day when the GPs disengaged from the partnership in protest (see below) I awaited the reaction from the HSE. I thought finally I would see some drama in this arena. But as described, no drama occurred. The 'tea ritual' and 'role' culture were effective in setting the mood and tone in which any crisis could be managed or 'seem' to be managed.

> The 'Conference room' is a prefab, one of the many appended to the sprawling institution (once held 'psychiatric patients' now holds mainly health authority administrative staff).
>
> SC (PMs Assistant) makes the tea. I join her at the sink at one end of the prefab start to help. Paper cups teabags.. "Nice sandwiches" everyone agrees.. "Bought in" we're told.
>
> Chat is about the sandwiches.. how nice they are... "The kitchen in the adjacent building is now closed because of mice infestation" PM informs
>
> "Isn't the pest control office based here?" I ask
> "Ah yes" says PM "but it's the pest control for the south side" she smiles as she sees the irony.
>
> There is only brief mention of the GPs not attending. "The North development groups have asked for their support" PM informs others as they seem more interested in the sandwiches.
>
> PC another manager arrives. The mood is friendly, informal and everyone settles down to business. (PO notes: management team meeting Oct 2005)

Rushing and reactionary

The GPs lack of 'time' impinged on how things were done and untimely their own influence within the space. One longstanding GP on the management team said:

> 'It (the agenda) was usually controlled by the chair, we were too busy and didn't have the time' the Chair was the most senior HSE official present.

But he felt everyone had an input. Considering what is in front of them only when it is in front of them is what GPs do (as in a GP patient consultation). It makes them quick, decisive and responsive. However this meant that GPs by default left the review and control of what would be discussed to the health authority. It also meant that though the GPs identified priorities for action at the AGM little or no pre-meeting preparation went into this. One health authority management team member pointed out, "it seems to be whatever brain wave comes on the way to the meeting". Poor response to circulars, surveys, and anything sent out for the GPs to read and gain feedback on was also, according to the GPs, a result of being pressured for time as a result of the high demands placed on them.

While the management meetings appeared cordial the General Meetings were more confrontational. This came through the archived minutes from earlier years also. One HSE staff member commented to me that the GPs had to be seen by their colleagues as "giving the HSE socks." Indeed some GPs did commented to me that the reason the NICP had such good services was because the management team members were such strong negotiators. It was necessary for the GPs to be 'seen' to play hard ball with the health authority.

Interests were also obviously different. The health authority was mandated with the responsibility to provide appropriate, affordable health care to the population whereas the GP have a very real commercial interest. Ivan Perry Chair of National Committee on Primary Care pointed out;

> "If a GP invests heavily in a team based care, well they'll obviously improve the quality of care, but they'll also increase their costs without necessarily having a commensurate increase in their income."

Creating a space to involve community

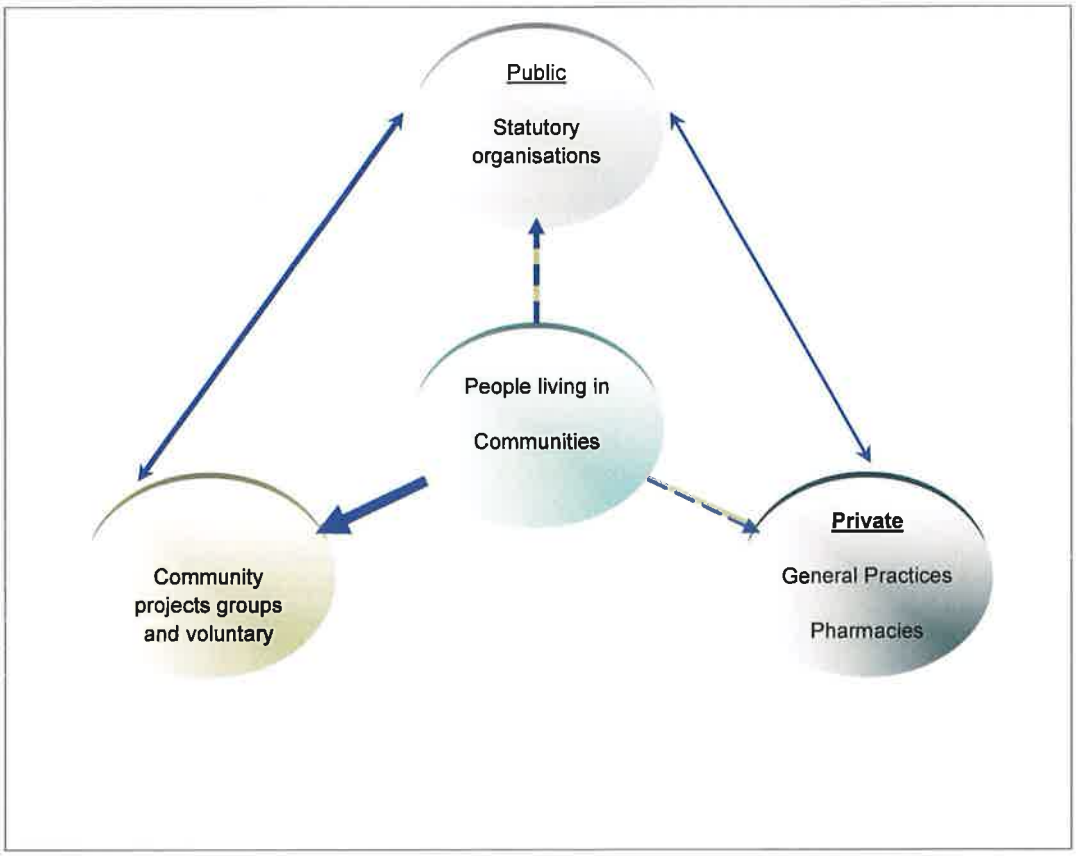
I presented my findings of my initial explorations in the inner city to the NICP at the February (2005) General Meeting. I concluded with the finding that there was no engagement between 'community' and GPs.

My presentation made the following points:

- The NICP is a heterogeneous area containing areas of affluence and deprivation. While indicators of deprivation are improving over time there are signs of entrenched deprivation in some communities
- There is a strong and vibrant community sector and network organisations.
- There are many partnerships where community and statutory agencies including the health authority engage.
- While there are examples of community groups engaging on health issues these are generally around the social causes of poor health rather that health services.
- GPs are based in the community but not engaged with community as a collective or involved in community agendas

I presented the following mode (Figure 20) to depict opportunities for influence among the various stakeholders.

Figure 20 Potential for influence. Presented at NICP General meeting 2005



The arrows show pathways for possible influence (thickness denotes strength). The model therefore shows people in communities can influence the local projects and groups through their membership in these as member's leaders or workers. People in communities can influence statutory bodies through political representatives and voting (though participation is low in the north inner city). People influence private service providers (GPs, Pharmacists, Dentists) as consumers through market forces.

The two way arrow shows two way pathways for influences. Community sector have links with statutory organisations through community development processes and workers and engagement in a number of partnerships. Statutory bodies can influence community through funding and engagement in partnerships. Statutory bodies can influence private service providers through contracts and financial incentives. Private services providers influence statutory bodies through representative bodies, partnerships and contracts.

There were no pathways of influence between GP and community groups. The GP initiator of this research project [PC] proposed that links should be established. While there was no resistance to the proposal, people were still confused about what that meant. One GP asked if we were talking about GPs being involved in writing up clothing grants for the poor[40]. PC volunteered to head up a group to engage with the local community on behalf of the NICP. No one objected; however the Health Board General Manager proposed involving the HSE Social Inclusion manager. No decision was made on the night.

At the next management meeting (Feb 2005), there was agreement that the NICP should attempt to engage with the formalised community sector in the north inner city area. Discussion at the subsequent management committee meeting reflected how decisions were made.

> The GPs at the management committee were in support of the idea to attempt to initiate dialogue between the GPs and 'the community'. There was some confusion over what was agreed from the General Meeting. At this point the HSE General Manager

[40] Health Board Community Welfare Officers (CWOs), had the ability to provide money for clothes for those in need. One of the requirements they sometimes asked for was to get a clothing grant form signed by their local GP.

suggested that the people working with the community on the ground should be consulted. Most important among these was the HSE community development worker (CDW). He suggested that the HSE Social Inclusion manager convene a meeting with relevant and experienced people working in the community including representation from Community Welfares officers and Nursing. At this point AOC (GP) made an attempt to have the GPs take control of the process

'Well you know, I would want us [GPs] to be responsible for this'

The General Manager assured him that the Social Inclusion Managers would literally convene the meeting and then 'it would be up to the people involved to take it from there'. (PO notes: management team meeting NICP Feb 2005)

Though convening the meeting to talk about creating a space for community involvement in Primary Care was presented purely as an administrative function, in effect this function influenced who was invited into this space. People invited to the meeting were those who the HSE General Manager suggested. The meeting held was attended by 2 GPs from the NICP, 2 HSE Community Welfare Officers, a Public Health Nurse representing the nursing director and the NICP project manager (all either HSE staff or GPs). The CDW was unable to attend.

Constructing community

Being constructed as 'beneficiaries', 'clients' or 'citizens' influences how people are perceived to be able to contribute, what they are entitled to know, or decide, as well as the perceived obligations of those who seek to involve them(Anderson, Florin, Gillam, and Mountford 2002a;Anderson, Florin, Gillam, and Mountford 2002b;Pickard and Smith 2001). Furthermore, how people are constructed by others, and how they perceive themselves to be constructed, means that within spaces for participation positions are never neutral (Cornwell 2002, 2004).

The meeting to explore how such an 'invited space' might be created took place in August 2005 (six months after the decision to hold it). The purpose of the meeting was to explore why links should be developed between the NICP and local communities; who should be involved, and what agendas should be explored?

Meeting participants were committed to the idea that there should be some dialogue between Primary Care providers and community members. They were generally positive about the

initiative and there seemed to be both the possibility of funding from the HSE and consensus that this should not just be about bringing GP and community together but about Primary Care providers in general and community groups.

Discussions were about what form this should take and who would represent 'the community' and what would be discussed. Options included a broad approach to develop an agenda or a more targeted approach with predefined specific issues.

The HSE General Manager suggested quarterly meetings with community representatives and health care professionals about issues they bring up in an unplanned way. He saw the HSE CDW as being instrumental in advising how links could best be built. He showed an understanding of how community groups functioned:

> *'just see what comes of it in terms of giving them an opportunity to breathe....some communities don't like it all worked out and then we going to them... they like to be there from the very beginning.'*

He believed that health needed to be put on the community agenda.

More focused approaches on topics or issues with tangible outcomes were also discussed and AOC gave the example of his involvement on the 'We're People Too Project' discussed in the last chapter.

One of the CWOs described his experience in Finglas where communities had been involved in a health needs assessment. This had identified health needs and served as a plan to follow to "tailor a response to that".

The General Manager was reticent about starting with a health needs assessment which would suggest the exercise of power in how knowledge is produced (Foucault 1984).

> *Because in the situation going forward it is about needs assessment if you don't set out in a scientific professional way about the needs of local communities you're not going to get the resources that are required to meet those needs so everything from here on in*

has to be needs based and priorities will form from that So I think we have to facilitate and empower and give them information that they can understand before we set out on a needs assessment (GM Community Involvement Group NICP).

The General Manager's view also saw community involvement according to what Morgan describes as a 'utilitarian' effort by donors or governments to use community resources to offset the cost of providing a service (Morgan 2001a).

We don't necessarily need additional resources, that's a another factor if we can work in a better way in a more co-ordinated way if we can utilise our resources better than we are currently and if the community could assist us in doing that and they may be able to inform us of better ways of doing things that were not doing etc., so to get that dialogue we need communication we need engagement (GM Community Involvement Group NICP)..

This first meeting to look at linking the NICP with the community sector in the area was successful in generating interest and commitment as well as bringing GPs together with other HSE PC members like CWO's who they would not otherwise meet. Options discussed included quarterly meetings to engage communities in the development of a common agenda, consulting with community groups on specific issues of relevance to providers , and communities e.g. drugs, medical cards, access to medical care or through a health needs assessment.

The meeting concluded with agreement that another meeting would be arranged. The GPs disengaged from the NICP and this never happened. If the NICP had survived this sub group would have provided a useful point of contact for the developing Health Action Forum in the north east of the city, the Blackhall community Forum in the northwest and the Grangegorman working group of the NWICN which was trying to influence then Primary Care Centre development. However this did not happen and this one subcommittee meeting represented the end of the NICP attempt to bring community voice into its space.

Closing a Partnership Space

This section traces the lead up to the closure of the NICP following three General meeting and discussions in management meetings which focused on the NICP as an entity[41]. It demonstrates the impact of power relations in other spaces and confirms that as Hickey and Mohan (2004) suggest, spaces are not discrete or singular but impact each other.

Harmony

The first General Meeting of the NICP I attended at the Maple Hotel in June 2004 provides a sense of a working Partnership where relationships are good and GPs are in control.

> The venue was a small hotel in an affluent area close to the city. The event had a distinct social tone. It was held in the evening to increase the numbers of GP attending. The tables were arranged in a large rectangular formation with white table cloths and single flowers in vases. The buffet style food and wine was arranged on tables lined against the side wall.
>
> At 7pm the PM told me that we would have to leave while the GPs met alone. We filed out to another room where we were joined a bit later by more Health Board staff (GP Unit doctor, director, and General Managers of the two Health Board administrative areas CCA 6 & 7). I did not understand why the GPs wanted their own private meeting. None of the Health Board staff offered any explanation other than this was just "the way the GPs wanted it".
>
> After about 30 of 40 minutes the HB staff joined the GPs for the main meeting. Updates were given and discussed and GP priorities identified as - access to diagnostic services (X-ray and ultrasound) and a Physicians Access Line (PAL) to the Mater Hospital. Health Board staff gave summarised reports on new initiatives addressed during the year

[41] Between October 2004 (when I finally received approval to attend management meetings) and December 2006 there were 10 management meetings held. I attended seven of these. I was not permitted to attend two and I was out of the country for one. Between June 2004 and December 2006 there were three General meetings of which I attended all.

included; basic life support training for GPs, development of a Pathway for the management of leg ulcers between community services and the Mater hospital, a forum between the NAHB and the National Children's hospital among others. (PO notes: June 2004)

After the general meeting it was business as usual back at the management team meetings with follow up of issues from previous minutes. The August meeting was deferred to September because the most senior HSE exec could not attend.

Changes in personnel who had helped build up the NICP as well as those in powerful decision making positions contributed to the demise of the NICP. Leadership and 'ways of working' are more important in 'invited[42]' spaces where contracts or structures have not been in place to protect partners' interests. In August, 2004 the Health Board employed PM of the NICP who had been in place for a number of years was transferred to another area and replaced with a PM who had a different style of working. The outgoing PM saw herself as working for the GP group and management team. In keeping with the 'role culture', the new PM sought clarification on the reporting hierarchy, which was confirmed as Health Board GM in CCA 6. The following February saw the resignation of the GP Chair who had been in place for 7 years. The establishment of the HSE meant that there would no longer be a high ranking NAHB executive involved. The loss of institution in the form of committed and senior people who had established the NICP made it more vulnerable in the context health system structural reform. Whether personnel changes were made for this purpose can only be surmised.

In retrospect subtle changes including the absorption of NICP staff into CCA6 allocations in November 2004, should have warned GP members of an alignment with HB structures rather than the NICP as an entity with its own staff. Other decisions at the same meeting such as deferring the issue of the election of a Chair and review of management team role until "more was known about the programme of reform" did not strengthen the NICPs position to survive a restructure. This prompted the GP Chair to ask if the Primary Care Unit (which dealt with GPs and secured NICP funding) would remain in place. The General Manager could not answer this

[42] While technically this would be describe by Garventa and colleagues as a 'closed' space because it did not allow for involvement of citizens lay people or services users, from the GPs perspective it was an 'invited' space as the Health Board had opened it as resourced it.

and commented that they (Health Board staff) were "going ahead blind because of Health Board changes."

On the first of January 2005 the HSE was established and assumed the responsibility for the management and delivery of health and social care services. The Eastern Region health authority and Health Boards were dissolved and their staff and assets transferred to the HSE.

Questions about the viability of the partnership in its current form (defined by current boundaries) crystallised at the management team meeting in January 2005. The PM informed me that I could not attend the meeting as there were 'sensitive' issues to be discussed. This was the last management meeting attended by the assistant CEO of the NAHB. The meeting was informed that the NICP would now come under to separate administrative areas (see table 12).

This structural change fundamentally threatened the NICP as an entity. It had been created by the NAHB across two Health Board administrative areas CCA 6 and CCA 7. It progressed initiatives and developed services through funding raised by the Primary Care Unit which was part of the NAHB. Having to, 'negotiate with two LHOs' effectively meant splitting the NICP in two.

This news was brought to the NICP GPs at their net General Meeting. This time I was permitted to observe the GPs 'private' meeting.

> NICP General Meeting February, 2005
> The GP meeting started. There was no reaction to people's lateness or apologies made. By the time doctors stopped coming in there were twenty around the table. Discussion was unstructured. TC chaired the meeting and briefed members about some of the issues arising from the management team meetings. There was no formal agenda. People were unsure about the future of the Partnership in the context of changes in the Health Board. Some people felt they should not have to change just because the Health Board did.

"why should our boundaries change and modus operandi just cause the Health Board is" one GP asked.

Disagreement

The discussion moved on to the services they had prioritised. The need of GP access to X-ray services was discussed. The GPs wanted commitment to the things "we have been promised". I noted comments showing disappointment turning to defiance;

"we were promised"

"we need guarantees"

Another asked, "Why come to meetings if nothing is going to come of them?" There was a sense of disillusionment.

The HSE staff (Project Manager, Assistant CEO, Area Medical Officer, two General Managers and Director of Nursing) came in and sat along the short end of the rectangle arranged tables at the back of the room.

AOC had been given the role of reporter by virtue of the fact that he had been the only one taking notes.
"The GPs did not want to split the partnership" he reported.
He invited others to include anything he had left out but there were no additions or disagreements with his representations of their discussions.

The Assistant CEO NAHB responded to AOC's representations of the GPs request for information and their priorities. She repeated a number of times that she would be "frank and honest" and went on to give bad news.
"There will be no development funding for the Partnerships", she said
"there is a staff ceiling" and that she "doesn't want to make false promises".

The atmosphere was tense, GPs were exasperated and frustrated
"what are we doing here if there is no funding?" one asked.

The assistant CEO went on to deliver a monologue about the Táinste Mary Harney and her allocation of 10 million euro to alleviate pressure on casualty.

She mentioned a submission to the ERHA that 'they have a bid on the table' for funding for diagnostics the GPs had asked for. She said they have 'no control' she mentions that 'Out of Hours' is a priority. She talks of decisions, developments and changes "coming down".

> *I noted: She sounds as though the power of real decision making lies in hands of those higher up who pass these decisions down. I wonder who in the HA is 'involved' in decision making about Primary Care if they are not present at the table?(Reflexive notes)*

The GPs then respond with a quote from James Mc Cormack[43], saying that they receive what has been said with a "serious dose of skepticaemia" and asked her to convey this to *"those who provide".(PO notes: General Meeting 2005)*

At the next management meeting later in the same month the GPs reiterated the GPs desire to keep the NICP intact. The GM said that the LHOs under the new HSE structure would

> *"explore mechanism to maintain the current Partnership Boundaries".*

The issue was not discussed at the April meeting. At the June meeting, the GM gave the names of the two new Local Health Office (LHO) managers and announced his own departure (he had been transferred to another area). He said that the

> "LHO managers of area 6 and 7 *will have to decide on the geography* of the partnership."

The GPs restated that their membership, at the general meeting, wanted the NICP boundaries to remain intact.

In a dramatic turn of events the GPs disengaged from the NICP prior to the next meeting. They had been part of a wider group of north city and county GPs who had been negotiating with

[43] James McCormick Professor of Community Health from 1977 Trinity College. Author "doctor, The: Father Figure or Plumber" 1979

the HSE about delivering a new service. These negotiations had broken down and this led to their disengagement from the NICP (described below).

The next management meeting nevertheless went ahead even though one key partner in the partnership was not present. At the October management team meeting the absence of the GPs was hardly acknowledged. The PM briefly explained that the GPs had disengaged. A letter by submitted by them stated that the GPs,

> " are unable to attend further meetings of the North Inner City Management Committee and any sub or allied committees until the tender process for GP Co-operatives is completed and resolved." (Letter dated 5th Oct 2005)

The meeting format allowed the elephant in the room to be ignored;

> Minutes of the previous meeting were read and adopted. Matters arising were itemised and gone through one by one; Dexascan, no update; Nursing Assessment form; Nursing Service and so on. Items 'the new structure of the HSE', 'review of the role of the management team and 'election of chair' were deferred to a later meeting. An audit on the usefulness of the 'Red Directory' suggested to the PM that few used it and so it should not be updated. A decision on this was deferred to the next AGM, the setting of a date for this was also deferred.
>
> There was discussion about the future of the NICP now that the 'LHO 6&7 are now autonomous of each other' and each will be 'developing a relationship with the acute general hospital within its area.'
>
> There was discussion about how NICP would be more 'difficult to deal with' than other GP development groups because they had received more services than the others. A manager said that if she had heard it once she'd heard it a hundred times (from the other groups of GPs):
> "it's not about taking away from the NIC it's about bringing us up to their standard."
> The PM felt the reason why the GPs in the NICP didn't want to split was because of the improved access to clinical services, she said
> "If I was in the NIC I wouldn't want to split either"

> Those present agreed to write a letter from the group to LHO manager (who was also the lead in Primary Care) asking for meeting to discuss Primary Care strategy roll out and how it would affect the NICP. There was some musing about how they could send a letter from the Partnership without one of the partners i.e. GPs. They agreed to circulate it with the GPs first and not to put much detail so that, "it wouldn't be controversial."(PO NICP MT Oct 2005).

My reflective notes on the same meeting show that I thought the HSE should have challenging or confronting the GPs about their decision not to split the partnership.

> *The assumption that the GPs don't want to split because of the hard material gains needs to be challenged. In fact the assumption that GPs in the NICP are strongly beholden to this idea that they don't want to split is also worth challenging. Based on what I observed at the last GP meeting at the AGM the idea of splitting the partnership wasn't discussed thoroughly at all. (Refl NICP MT Oct 2005)*

At the next meeting (December 2005) the GPs were still, 'disengaged'. The minutes reflect that a meeting had been set up with the LHO manager (lead Primary Care) and the management team for the following January to discuss the roll out of the Primary Care Strategy and implications on the NICP.

The January meeting with the LHO manager took place with only one GP present and there were no apologies recorded from the others (disengaged as in previous minutes). The GP who did attend may have been unaware that attending this meeting was going against the GPs decision to disengage. The LHO manager presented a very high level and top down approach to the Primary Care Strategy roll out (see table 11).

I attended the next meeting in March 2006 at which the decision was taken to suspend all future meetings until "the GPs re-engage with the MT." Finally seven months after one partner disengaged the other accepted that there was no partnership. This was the last time the management team met until July 2006 when the GPs decided to re-engage.

The meeting was held to discuss the future of the NICP as well as to 'discuss the development of Primary Care Teams and Networks in Local Health Office areas, now named Dublin North

West (CCA6)and Dublin North Central (CCA7)and how this development would fit with the existing North Inner City Partnership .

There were two GPs present as was the North West LHO manager (HSE lead for Primary Care). General discussion ensued and one GP insisted that a mandate from General Practitioners in the NICP would have to be sought before there was any agreement to change.

Being left behind

The General meeting to discuss how the NICP would fit with the Primary Care strategy rollout did not take place until December 2006 (almost two years after the issue arose). This was not a 'usual' AGM as the project manager explained at the start of the meeting; its purpose was to discuss the Primary Care roll out and the future of the NICP.

> NICP General Meeting: December 2006
> I arrived at 7 pm. The venue was the Maples Hotel again. There was a small group of HSE staff and a small group of GPs sitting around talking in the usual room. There were no single flowers in vases there was no buffet styled dinner and wine. There were sandwiches, teas and coffees. This was not a social event.
>
> The room began to fill up. There were about 25 by the time the meeting started. There were two LHO General Managers and director of Primary Care unit. There was no pre meeting held by the GPs this time.
>
> The meeting started with a presentation by one of the General Managers on how the Primary Care rollout is working in North West Dublin (previously CCA 6). It was called the 'PCCC transformation project'. It was detailed and jargonised and I wondered how many of the GP would be familiar with some of the terms. The local implementation teams (LIT) she said were comprised of the General Manager, Director of Primary Care, representatives of 'P triple C' (Primary Community Continuity Care), frontline services including community, mental health, and addiction services representatives from acute hospitals, general practice/faculties and the community and voluntary sector. They had been meeting regularly since June. The role of the local implementation team was to

provide leadership and direction to the implementation of the Primary Care model in North West Dublin. (PO *NICP AGM Dec 2006)*

My reflective notes read;

> *This presentation was given by the general manager and delivered very speedily without pause or opportunities for checking for clarifications or understanding. Much of the language was HSE speak which I felt sure went over many heads.. transformation projects ... implementation teams... networks. There was an assumption that everyone present had studied the Primary Care strategy and related HSE developments and documents line by line and word for word which I was sure they had not. However neither was there any acknowledgement of lack of understanding on the part of the GPs (Reflective notes NICP AGM Dec 2006)*

It was evident to me from this that these new 'implementation' teams were (in theory) now responsible for Primary Care development in the HSE local administrative areas. They were established by the HSE in line with their own admin structures and direction. They were now the working mechanisms for engagement, at least in principal, between the HSE and the community and voluntary sector as well as with GPs.

However, I felt there was a feeling of frustration and powerlessness among the GPs who attended the meeting. The HSE were getting on with the business of rolling out the Primary Care Strategy and structures had been established in LHO areas to guide and oversee the establishment of Primary Care Teams in the areas.

The meeting format showed the HSE providing information on how the PC strategy was being rolled out and the GPs responding. Many GPs articulated that they felt 'left out'. And wanted to know what they should do if they had not been assigned to a PCT. There was much discussion about which areas GPs' patients lived in. According to the HSE tis would determine which PCTs GPs would be on. The HSE had plotted each GPs medical card patients across the map. There was the sense that if a GPs patient list did not fit neatly with a PCT then the GP was 'left out'. AOC said his practice was on a border area (between CCA 6 and 7) and so he felt he was being left behind. (In fact he had patients in what had been defined as six different PCT areas. Others said they were 'not involved'.

The LHO manager (PC lead), assured GPs that nothing was set in stone and that various models would be looked at and that they were open to "expressions of interest." And all GP were invited to "express interest".

GP weren't happy they felt they were being *"left behind by a system based on [map based] divisions"*

General gripes were aired by GPs

"are we simply being given more [of a] work load?"

" will we be paid for extra work load?"

"young GPs not setting up in the NIC?"

"ours is a demoralised needy population?"

Discussion was brought back in the end to whether the NICP should continue. A management team GP offered the suggestion that the NICP would continue;

"until GPs felt included in other processes they could not disband it (NICP)."

There were no objections so it seemed to be taken as consensus among GPs. There was no vote on this issue.

No date was set for the next meeting. (PO notes General meeting Dec. 2006)

Table 11: Management & general meetings influenced by structural changes

Month	Meeting type	present	Minutes relating to factors challenging existence of NICP (June 2004 –Dec 2006)
June	General meeting	All GP members & MT	***GPs identify the priorities***
Sept	MT	3GP 5HB + ass CEO	2 nurses posts absorbed into CCA6 allocation PM report to GM CC6
Nov		4GP 4HB	Discussion of review of MT role to defer to new HSE structures
HSE established → Jan 2005		2GP 5HSE +ass CEO	Local Health offices will have responsibility for budgets, staff ceilings etc. -(The) North Inner City Group will have two LHO's to negotiate with. Previously Swords HQ would have brought the two areas' together but this is not the case anymore. -The North Inner City Group needs to address this issue in 2005
Feb 2005	General Meeting	all	***GPs are left disillusioned having been told-No further development money for NICP which is in conflict with new structures***

	Feb 2005	MT	3gp 3 HSE	Interest of GPs – maintain NICP as 'natural partnership' HSE – LHOs being established then NICP as an entity could be 'explored'
	April 2005	MT	2GP 5HSE	HSE- Reform will result in amalgamation of all community services including mental health and addiction services
	June 2005	MT	3GP 3HSE	Ass CEO no longer mentioned as apologies HSE- the NICP does not necessarily reflect the organisation and structure laid out in the PC strategy i.e. having services ring fenced. The strategy promotes integration of all services involved in identified Teams and networks GP – suggest GP MT meet to discuss Primary Care strategy impact on NICP HSE- defer election of chair and review of MT due to 'Reform of Health Services' HSE announce new LHO managers for 6&7 and GM 6 on T transfer PM question need and purpose of newsletter PM to present findings of Red directory before decision made not to up date Consistent GM leaves , no chair in place
Negotiations re 'out of hours' service breakdown	Oct 2005	MT	6 HSE 0 GP	GPs **disengage** from MT letter from GP MT members – " after consultation with GPs in NICP, we regretfully are unable to attend further meetings of the North Inner City Management committee and any sub or allied committees until the tender process for GP Co-operatives is completed and resolved" PM writes to LHO manager 6 (lead on PC strategy) to seek a meeting for MT on future of NICP (letter copied to HSE MT members but not GPs)
	Dec 2005	MT	4 HSE 0 GPs	LHO managers will be accountable for managing all strategic responsibility in area LHO 7 manager, reports on meetings with Mater to develop linkages -communications committee special meeting re Physicians access line "the demand and demonstration of value of PAL was not evident". The pilot project ceased 17th Nov 2005 - MT to meet PC lead LHO manager 6 19th jan
	Jan 2006	Extra ordinary meeting with LHO6 (PC lead)	5 HSE 1 GP	LHO6 manager informs: *The CEO of the HSE Prof Drum had appointed Dr S Maguire an Advisor to the Primary Community and Continuing Care (PCCC) who in turn has established a group to look at the Primary Care Strategy.* (This group comprised of The National Care Group Manager for Primary Care services the assistant National Director Planning monitoring and evaluation and the Assistant National Director of PCCC). There was general discussion of what was working well and w*hat needed to be developed* (PCUs with on site diagnostics).

			The GP present agreed to talk to GP colleagues about Primary Care developments and their 'priorities'. It was suggested that this could be discussed at the GP General meeting
March 2006	MT	4 HSE 0GP	General agreement of all present that until GPs re-engage with the management team that all future meetings are suspended
July 2006	MT	4 HSE 2 GPs	**GPs re- engage** **Purpose – to** 'discuss the development of Primary Care Teams and Networks in Local Health Office area's Dublin North West and Dublin North Central and how this development would fit with the existing North Inner City Partnership' (NICPMTmin130706). The GPs stated that a mandate from General Practitioners in the north inner city would have to be sought before decisions could be made on the NICP. There was agreement that the NICP would remain as is for the foreseeable future (ibid).
December 2006	General Meeting		**GPs feel left out as Primary Care Strategy is rolled out, with or without them**

Agreement is reached in negotiations on 'Out of Hours'

Opening a Partnership Space

The GPs kept certain discussions outside the NICP space. The development of the 'Out of Hours' services in North Dublin was one such development. At the start of my field work I had identified this as a potentially 'significant' development in Primary Care which could impact services in the north inner city. Therefore while I was observing what went on within the NICP space I was also monitoring this potentially 'significant' service developing outside of it. The HSE had for a long time been clearly interested in developing a more satisfactory 'out of hours' service for the half a million people in the north Dublin region. I noted from the NICP archives that four years previously development of an 'Out of hours service' had appeared for discussion. Sometime later however it had been taken off the agenda by the GPs stating that 'GPs are not in a position to pursue this project in the short term' (NICP 2001). In Assistant CEO NAHB Michael Walsh, highlighted that the development of 'out of hours' initiatives was being seen by the Department of Health as an important development to be pursued at a national level (NICP 2002). He also acknowledged at the same meeting that while the issue had been raised in the past by the Partnership it had been agreed that this was not currently being discussed by the North Inner City Partnership.

GPs saw this issue as being too big for the NICP to make decisions on. I therefore traced the development of the 'Out of hours' services in north Dublin to see who would be involved in decision making and how voice and influence would be exercised (GP key informant).

After approximately two years of negotiations between GPs and the HSE, an 'Out of Hours' service began operating on 28th November 2006. The negotiations and establishment of the service were lauded by the HSE CEO Prof. Drum as an example of successful partnership between the HSE and the North Dublin GPs.

> *"I believe that today's announcement reflects a good example of partnership between the HSE and GPs where patients clearly benefit. I would like to thank all the Northside GPs involved in setting up this service for all their hard work and commitment."*

The GP Medical Director also saw the service as an example of partnership between Local General Practitioners and the HSE(HSE 2006b).

At the official launch in February 2007 the Taoseach, Bertie Ahern congratulated all involved.

> *"I have taken a great personal interest in the establishment and development of this service and I know that a huge amount of work and energy was put into this project, both by HSE staff and officials at the highest level and of course by the General Practitioners of this community. I am glad to take this opportunity to thank and commend you for your hard work in planning, negotiating and finally working to bring this service into existence".*

I was first introduced to the 'Out of hours' during coffee with my key Informant GP (April 2005). For me at the time the meaning of the term 'Out of hours' was not self-evident. The GP explained that this was a proposed GP service which would operate *outside* normal GP hours, hence 'Out of hours'. Between 1998 and 2005 Irish general practice had developed 11 out-of-hours co-operatives, covering almost 40% of the population (Bury, Egan, and Reddy 2006). However, none had been developed in the north city or county Dublin. The service operating in the north Dublin was provided by a private company in Dublin, Contractors Medical Bureau. This company provided cover from the time the GP Practice closed until 8am the next morning. The service was provided at night by two GP locums who visited patients requiring treatment in their own home. GP's paid this company an annual fee to have their patients covered by the

service. In the south city, three General Practice Cooperatives were in operation providing 'out of hours' services for the patients between the hours of 6 pm to 10pm from Monday to Friday and between 10 am and 6 pm on Saturday and Sunday. After 10PM the Southside GP's used Contactors Medical or a similar company to provide Locum GP's to carry out emergency home visits.

Interests

While there had been efforts in 2003/2004 to establish a small Northside co-op by a group of proactive GPs in the north inner city the proposal had not received widespread support from the wider group of GPs based in North Dublin. The NICP GPs had not seen why they should "upset the apple cart" when there was no obvious gains. There was no financial incentive for GPs to provide this service themselves. As one GP explained;

> *"You contact night service, they charge you a set fee per year, and then they charge you per call, but they only charge you at the same rate. If it's a private call, they charge you €50, which they get straight off the patient. If it's a GMS patient the only charge is the amount that you would get paid by the Health Board. So, in other words, there is no stimulus to provide night time service, financial stimulus, because you basically end up neutral" (Interview with GP, NICP)*

However towards the end of 2004 a private company made representation to the Minister of Health to provide a commercial service for out of hours cover using GPs from overseas. The establishment of an 'out of hours' service became a significant priority for the HSE. Urgency on the development of the service came as a consequence of the Minister for Health's '10 Point Plan' to alleviate pressures on hospital Accident & Emergency Departments. This prompted a change of heart among local GPs. They feared that if GPs were brought in to establish an 'out of hours' service then there would be nothing to stop them setting up as regular GPs and encroach on their businesses (key informant GP). This coupled with the priority the HSE now placed on the development of the service prompted GPs in the greater north Dublin area to meet at the beginning of 2005 to discuss the development of a co-op which would provide out of hours cover. There was involvement from a "good proportion of the GPs" in North Dublin and 'closed' (GP only) meetings were well attended (GP on 'out of hours' committee). A

committee was established with representatives elected by the GPs to enter into negotiations with the HSE.

Negotiations

The HSE announced that "Discussions have commenced with GPs on the extension of out of hours and weekend GP cover, and the HSE has engaged with the private sector on how they might support the A/E service" (HSE 2005a).

Negotiations between the GPs' elected representatives and the HSE high level executives including the HSE CEO's advisors, continued through-out 2005 with to-ing and fro-ing from both sides.

At the end of August 2005 a significant meeting of the GPs with the HSE was held. At this meeting, (according to my key informant) the HSE had "dropped a bomb shell on the GPs". They had decided to put the 'out of hours' co-op out to tender. The GPs were indignant. After all the work, planning and negotiations with the HSE they felt the HSE was now "pulling the rug from under them". One of the GPs on the negotiating committee later told me;

> *'In my 30 years of practice I have never been reacted to in that manner. It was a total insult'.*

The GPs went into reactionary mode. Within five days they had decided to stop all forms of formal engagement with the HSE. This included all committees and 'Partnerships' such as the NICP as well as GP development groups in the North Dublin area. The decision to 'disengage' was not made at the meeting but through a series of phone calls. The NICP GPs were not in favour of disengaging but felt that they "had to go along" with what the other GP groups were doing. One GP on the management team explained that he felt that he would be "questioned by the people he represents as all the others meetings were suspended."

Though a disparate group they had nevertheless very quickly resolved to act as one in defiance. Another GP on the NICP management told me that this strategy had worked for them previously. In the 1990s negotiations with the HB had broken down.At that time the IMO was successful in getting eighty per cent of the GP to tender their resignations on the GMS

contract. In the event no strike was necessary but the threat was there. I was told that "behind closed doors heads were thumped" and that the strategy had worked.

Two days after the HSE announced their decision to 'tender' the disagreement hit the news. GPs through the media criticised the HSE saying that,

> 'State taking over responsibility for out of hours service is a major departure from current practice' the HSE says it has invited 'doctors or private companies to tender for the provision of the service, which would be operated and overseen by the Executive'(RTE 2005).

Other co-ops being established vowed not to be bullied by the HSE. Dr Ryder said that Limerick GPs were angry at Junior Health Minister Tim O Malley's comments saying the HSE could step in and tender for the provision of service;

> "As GPs we are completely independent from the Government we will not be directed on how to structure our out of hours service and we won't be bullied into joining any co-op" (Lynch 2005)

Never the less the north Dublin doctors did tender for the provision of services. The original company which had made a presentation to the minister was "convinced" by GP colleagues not to tender. Two other groups also tendered, however one was revoked when potential 'conflict of interests' was pointed out by some among the north Dublin GPs. Finally there were only two tenders on the table. These were the north Dublin GPs incorporated as a company and another company which was currently providing services on the south of the city.
In March 2006 the HSE revoked the tendering process stating that;

> 'the submissions received during its tender process to secure a supplier for Out of Hours GP services in North Dublin did not meet the quality standards required'(HSE 2006a).

This was curious as the one of the groups tendering was already providing services and the other ended up providing the service. A later analysis suggested that

> 'the Executive and local GPs were close to agreeing a contract at the time but the HSE wanted penalty clauses, relating to performance, included in the contract. doctors feared this would have made directors of the co-op personally financially liable for these penalties' (McGuinness 2006a)

In April there were reports of positive negotiations between the IMO, who had become involved on behalf of the GPs, and the HSE (IMN 12/05/2006). The Chairman of the Irish Medical Organisation (IMO) Mr George McNeice had been written to 'directly' by the CEO of the HSE Prof Brendan Drum. This marked the first time the IMO at national level has negotiated a for a local GP Co-op (McGuinness 2006c). By end of May the medical media was reporting agreement in principle by both sides and that the controversial performance-related penalty clause had been dropped and that the IMO was recommending acceptance of the deal which would provide local doctors with 'advance payments to launch the Co-op.' The money would provide for locums, information technology and other infrastructure (McGuinness 2006b)

A deal is struck

At a "tense" meeting on the 8 June 2006 the GPs were balloted on the out of hours deal. It was presented to them by Dr Martin Daly IMO Chair who urged them to accept. Some GPs expressed concern that the local GPs were being "rushed into agreeing a deal", and others felt that a joint IMO/HSE press release stating a deal had been agreed in principle was "totally unacceptable". The Chair of the Coop steering committee recommended acceptance of the deal to the group. The GPs voted to accept the deal. The Service Level Agreement had not been signed so while the main elements of the 'deal' were in place finer details were left to the management committee to tease out.

In terms of outcomes both sides were happy with the final agreement which the HSE had to drop the issue of full population cover (only patients of GPs taking part in the service would be covered) they were successful in getting the service they had originally planned and described in press release announcing (HSE 2005b)

A GP on the Out of hour's GP Board of management evaluated the outcome;

"The HSE got a more expanded service than we had originally envisaged while we got more money and flexibility around employment of locums"

Ready to roll

In September 2006 I visited the North Strand Health Centre which was to be the 'Out of hours centre' in the north east inner city. The HSE had invested over a quarter of a million euro into the previously run down Health Centre to give it 'a complete face lift'. Staff were being trained to man a telephone centre for patient triage and drivers, nurses and security staff were being recruited, trained and put in place. A significant amount had been planned and put in place without the GP's engagement in the process. The HSE had aimed to have the service up and running by September but this was pushed back to November due to GP opposition.

The GPs had established a company limited by guarantee called Northdoc Medical Services Ltd and signed a service level agreement to provide GP 'Out of Hours' services to the HSE and hired a manager. The HSE publicised and launched the service using the name 'D Doc', as a service provided by the HSE. Nevertheless as I have highlighted at the start of this section, once the service was up and running it was considered a partnership by both parties concerned.

In the first few months of operation it appeared that the GPs and HSE were 'working well together'. The difficult part, getting a contract signed by the GPs was past. The Service Level Agreement (SLA) had finally been signed by the GP group only days before service implementation. They recruited a manager for 'North Doc' (the company established by the GPs) who reported to the GP Board which a medical director with specific responsibility for medical governance and standards. On the HSE side there to was a manager of the D Doc service who was line managed by the HSE LHO North West manager (lead in PC). There were monthly meetings between both managers and quarterly review meetings between GP directors and HSE. In contrast to the latter period of the NICP there was a high degree of devolved power so that any arising problems could be dealt with immediately. The medical director noted that

"on this occasion there was a lot of money to be spent on this project and it was available and therefore, the HSE came up with the goods in terms of providing adequate premises, adequate cars, staff, all the rest of it, and you know, when they

have that then, it's, it's really time for us to show up and jump on board, the train is leaving, and I think that's what happened with most people."(Interview with medical director North Doc)

Discussion: Space Power and Interests

I had considered the NICP space as a space for Primary Care decision making. Prior to the restructuring of the health system the Partnership did improve the services that GPs offered through joint decision making and financial support from the Health Board. However as one GP commented the scope of decision making was relatively narrow. Once restructuring was on the cards significant decision making power was not devolved to this space. Senior managers and health authority executives passed information to the Partnership and awaited decisions to 'come down'. Imminent restructuring created an environment in which it appeared that role culture was co coordinated by a thin layer of senior management with decision making power at the top (Handy 1981).

The Health Board's interests were two fold; they wanted to repair relationships with GPs who they had little direct control over, but they also wanted them to provide services which were being provided by the hospitals (e.g. warfarin clinics, diabetic shared care). This was a conflict of interest as one GP put it;

> "The partnership was to develop services and foster good relations but also I believe there was a sub agenda on the part of the Health Board to endeavour to get us to take services out of the hospital without paying us to do so (GP Management Team NICP)."

Indeed the purpose of Primary Care is to keep people out of hospital and deal with as much as possible in services in the community thus providing more affordable care (Department of Health and Children 2001a). The view of Primary Care which arises from the NICP space is one that is dominated by hospital rather than community. The impetus for creating the space was the loss of the hospital on the Southside of the city, the NICP boundaries were drawn with reference to the Hospital's catchment. Much of the Partnerships activity was around improving the Hospital GP interface. This fact coupled with the lack of engagement with frontline Health Board staff in the community sees the GPs as part of the hospital system based in the community; the gate keeper to the hospital system.

The Primary Care Strategy and restructuring of the health system saw a fundamental shift in this view of Primary Care which meant there was no room for the previous model. GP were to become part of other community services and work in teams. Dr Ivan Perry describes GPs discomfort with this;

> My sense is that the GPs were always a bit ambivalent about the Primary Care Strategy and I suppose, for one thing they're not entirely comfortable with the concept of Primary Care, they're more comfortable with the concept of general practice, which is a clinical discipline, and, which is obviously led by doctors, whereas obviously Primary Care is more community oriented multi-disciplinary team based model. (Interview with DR Ivan Perry)

The HSE had no interest in maintaining a structure which did not fit with its new plan. Actions were taken to diminish work associated with this space (Red directory not updated) as they would duplicate what would be done in other spaces under the new HSE (e.g. Directory of services in LHO 7). However as we saw in chapter six, decision making was far from explicit and confrontation was avoided.

Lukes (1974) tells us that consensual authority with no conflict of interest is not a form of power. Whether rational persuasion is a form of power is open to question. But rational persuasion was not utilised at all. I found it odd that the GPs position on boundaries, and whether that position was the view of the majority, was never challenged. The last General Meeting indicated that GPs did not want to be left behind and this suggested that they were open to negotiation. In fact their reaction 'not to split' appeared as a reaction to the use of power; being told (though not explicitly) that they had to split. Once again non-decision making was used to achieve the outcome that the HSE desired. This time non decision making was used systematically on issues which might strengthen the Partnership; role of management team and election of chair were repeatedly deferred. No explicit decision was made by the HSE about the entity of NICP, it was never explicitly closed. However in practice no more meetings were arranged and the Project Manager and admin staff were transferred to other positions in other areas.

The exercise of power in this domain saw the 'mobilisation of bias' or rules of the game which is sustained through non-decision making (Lukes 1974; Garventa 2006). This two dimensional

view sees a set of predominant values, beliefs, rituals, and institutional procedures operating to the benefit of certain persons, groups and perspectives at the expense of others (Bachrach and Baratz 1962). The 'rules of the game' in the NICP benefited the interests of the health authority and were strictly adhered to through the role culture. The minutes, agenda, and organisation of subcommittee meetings, were in the control of the health authority staff. Under these rules, meetings continued while partnerships had been disengaged and were not continued, even while Partners expressed a desire to continue. The GPs private meeting which I had misinterpreted at the start of the study as an exercise of power I see now as an attempt to claim a space within which they could speak freely without being influenced by the rules of the game and power differentials.

The making explicit of agreed 'rules' by which the partnership would operate including the reporting of the Project Manager to the management team rather than one of the General Managers as well as the decision making process, would have made it necessary at least for decisions to be explicit. However the GPs 'task' or 'person' culture did not encourage them to insist on 'role culture'/ bureaucratic mechanisms.

According to Gaventa (2004, 2006) and Cornwall's (2004) typology, the NICP is technically a closed space; decisions made by a set of actors behind closed doors. Despite excluding lay people/ public had a lot of 'transformative' capability. This capacity included the potential to engage with local community and embrace and contribute change in terms of the restructuring of the health system albeit at a local level. This potential was not exploited.

The development of the 'Out of Hours' services sees an extremely closed space for significant decision making. While policy rhetoric expounds the virtues of community involvement in health service planning and development, this development actually excluded any form of community representation from the frame. A decent service resulted, and policy makers applauded the partnership process. Though the process resulted in a partnership (this time with agreed 'rules') the process saw conflict and the exercise of power through 'coercion' according to Bachrach & Baratz (1962,1970) view of power. This was achieved by the HSE 'threatening' to deprive the local GP of the contract which would potentially affect their businesses, by bringing in foreign GPs to run the service. It also saw coercion within the GPs in

order to eliminate competition and present a united front. If coercion overstates the case, manipulation (a sub form of coercion) may be more applicable.

Lukes (1974) defined the concept of power by saying that 'A' exercises power over 'B' when 'A' affects 'B' in a manner contrary to 'B's' interests. So far analysis in these closed spaces see the health authority as exercising power to achieve it own interests. However its policy interests are intended to represent the interests of the people. Talk of interests, according to Lukes provides a licence for the making of normative judgments of moral and political position. It is possible to link public interest to the development of the 'Out of Hours' service, in principle. For the preceding two years there had been public out-cry at the over-crowding in hospital A&E departments which resulted in Minister Mary Harney's '10 point plan for A&E'. This included the development of an 'Out of hours' service on Dublin's north side.

The GPs interests in maintaining boundaries could not be linked to the public's interests. Issues raised by communities were worlds apart from priorities suggested by GPs. Certainly, the GPs commercial interests which prompted reluctance to 'take things out of the hospital' or develop an 'out of hours' service could not be linked with community interest.

However assuming the health authority interests are in tandem with community interests would negate the need for the community, customer, and public involvement which it calls for. The very purpose of policies aimed at involvement is to ensure that service development is in the interest of the people they serve. While there are problems associated with the representation of those interests within the 'room' including the risk of tokenism legitimisation, there are many ways of ensuring actual interests are represented and 'voice' is heard. Being able to show one is in fact representing community/public and being supported by those interests will undoubtedly influence how power is exercised. This was not attempted however and other less transparent forms of power were exercised.

Chapter 10 Conclusions

Tommy let me into his small ground floor flat in a Local Authority flat complex in the heart of the north inner city. After nine years of homelessness he was allocated this flat by the Dublin City Council and had been approved by the local tenants committee who vetted new comers. He had moved into the flat nine months ago.. He is appreciative to Bob the outreach worker from the drug treatment clinic who had made a case for him;

> *"Bob went for me, the outreach worker, and he said 'the way it is everyone deserves a second chance. Ok he's on methadone, but what harm is he doin', he goes to the clinic.' Now, see the thing is now all the people around, it's after hittin' their own doorsteps [drug addiction] and they're only realising now, 'it's not his fault,' do you know what I mean."*

Tommy is 44 years old. He was born and reared in the inner city. He is unemployed and did not finish normal school because he was sent to an 'industrial school[44]' at a young age. He told me that he had been 'on drugs' for 22 years and had started injecting Cocaine while staying in a Health Board local hostel for homeless people. The hostel, which has since been closed, accommodated over 150 homeless people, mainly drug users. Tommy describes dreadful living conditions in the hostel. As well as his drug addiction, Tommy has hepatitis C which is not being treated. He also has leg ulcers. Nevertheless, he describes his health as good;

> *"It's grand thank God Fiona, I was tested there for HIV which is negative"*

Tommy engages with three Primary Care services who never meet one another. He gets his dressings changed on his leg ulcers three times per week at the local health centre, where he also uses the needle exchange. He receives methadone maintenance therapy (MMT) at the local authority drug clinic (City Clinic). Here he sees the GP once a month for 5 to 10 minutes. He does not go to the counsellor as he felt "she was getting too personal too quick". He receives dietary supplements and "a couple of Valium" from his family GP who is located on the outskirts of the city centre. The GP refuses to treat his addiction;

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[44] In Ireland the Industrial Schools Act of 1868 established industrial schools to care for "neglected, orphaned and abandoned children". These Reform schools were run by religious orders and were the sites of significant neglect and abuse.

"Umpteen times I asked him but he always says no, he says 'I'm not given out methadone' he says,' ye have to go to city clinic'"

F: OK. So do they look after your other health care in the clinic, like if you've a chest infection or a ..

T: No no, Fiona if ye have any health issues in the clinic you're told, go to your own GP. That is the rule now.

I asked him if he felt he had a say in decisions about his treatment:

"Ye have no say down there Fiona, you're told down there, 'if you've any messin' out of ye' down there you're told 'you'll get suspended off the clinic, or if you've any messin' at all you're goin' to get sent over to Pearse Street [Central treatment clinic]. Ye know. That's the bottom line of it. 'You don't tell us how to run the clinic we know how to run our own clinic,' ye know what I mean.

You're more or less told 'look it, mind your own business, we can run our own clinic. It's nothing got to do with you.'

Interview with Tommy June 2006

'A health system that encourages you to have your say listens to you and ensures that your views are taken into account'

Quality and Fairness. A Health System for you. Health Strategy. 2001

In summary

The opening of this chapter sees Tommy, an ex-heroin addict now on methadone. He is grateful to Bob the project worker at his clinic for negotiating with the flat complex tenants committee on his behalf. Given the various forms of structural violence he has suffered he is in fact lucky to be alive. When Tommy's project worker from the clinic entered Tommy's social world, Tommy got a flat and his addiction problems began to stabilise. In line with the social determinants model, methadone did not save him, housing did. However he now receives piecemeal Primary Care from separate services which according to policy should be part of one system and delivered by a Primary Care Team. Because of the stigma associated with heroin addiction his GP will not prescribe methadone. So Tommy has to stay 'on' the clinic and continue to be segregated from the rest of the community. Having 'a say' for Tommy would mean receiving primary care services as policy rhetoric intends.

Primary Care in the context of north inner city Dublin is seen in this study as a fragmented set of services delivered by the health authority and GPs. The national plan which intended to transform the health system to provide coordinated first level care to the majority of people through integrated team working has not made impact on the ground at least in the deprived areas of the inner city. Service provision was provided in parallel form with little consultation and less team working (Boon et al 2004). The fundamental problem of so called teams serving different caseloads from different services had not been addressed. This situation meant that there was no coherency in care provision leading to duplication and inappropriate care. This means that those in most need of a range of medical and social care interventions were unlikely to get them.

In contrast to the aims of national policy this study finds that communities did not influence formal Primary Care planning or decision making in the study setting. It finds barriers to the involvement of community voice in Primary Care planning and development and concludes that these barriers are even greater for the socially marginalised group - drug users. Barriers to local influence (including influence by GPs), included top down decision making, covert health service planning, fear of confrontation, a historical lack of health service development and the lack of an identifiable 'system' of Primary Care.

This last chapter brings together the main findings. The first part describes how power relations bolster decision making processes which exclude rather than include. I argue that the

spatial conceptualisation of participative practice is useful for identifying opportunities to democratise decision making. The second part of this chapter aims to further explain findings by interrogating paradoxes inherent in community involvement discourse. I use deconstruction to uncover incoherence in the ideology of community involvement in Primary Care in the context of lived practice in Dublin's north inner city. Finally I demonstrate how reframing of Primary Care not only achieves coherence but also 'results' in community involvement. I suggest that without such reframing, efforts should be targeted in a more focused way at democratising decision making in spaces where decisions occur rather than supporting broad development ideologies which become meaningless in practice.

Reality and rhetoric: Space, power and interests

In contrast to the aims of the national health and Primary Care strategies this multi-sited ethnography finds no direct community influence on formal Primary Care planning or decision making in the spaces explored. In fact it finds barriers to the involvement of community voice in Primary Care planning and development. It finds that these barriers are even greater for marginalised drug users. Barriers to local influence (including influence by GPs) include top down decision making, covert health service planning, fear of confrontation, a historical lack of health service development and the lack an identifiable 'system' of Primary Care. Barriers to involvement from the community side include the prioritisation of more critical issues for community action, an acceptance of the health status and services as outside its area of influence.

Patterns of behaviour in the spaces explored saw community members act and react (in relation to interaction with State 'authorities,' in a similar ways to the GPs. Both community and GPs identified the need to speak with one voice, the need to have representation, the right to protest or disengage and were at ease in confrontational situations. In contrast the health authority exercised 'role' culture avoided confrontation through the mobilisation of bias supported by deferred or non-decision making.

Participation as spatial practice

I followed Cornwall and colleagues to explore spaces for participation (Brock, Cornwall, and Gaventa 2001;Cornwall 2002;Cornwall 2004;Gaventa 2002;Gaventa 2004;Gaventa 2006). I wanted to see the effect and influence of community on health policy and decision making

within these spaces. However I could find *no space* in the study area in which Primary Care decision making took place where 'community' was also present. This was the first significant finding. This finding was contextualised by a vibrant community sector with a twenty five year history of community development, involved in a range of spaces for participation influencing 'factors affecting their lives'. The approach taken by the health authority in practice was broader than the permit stipulate in the Primary Care strategy. Community groups were funded, community welfare officers provided financial supplements for people in need and community development workers worked directly with groups. These activities often went on beneath the radar and were not highlighted as part of the health system. The health authority was engaged in many of the interagency partnerships. In contrast, GPs provided medical services and acted as gatekeeper to hospital services.

The community networks described here as *associational spaces* served to support and represent community groups in invited spaces for participation. The networks action plans did not include health (except in the context of drug treatment) until prompted by planned service development and this study. While there were many participative spaces in the form of area based initiatives to tackle disadvantage, drugs and development, there was none specifically for health.

The NICP space was established as an *invited* space by the Health Board to improve relations with GPs and between primary and secondary care. Though seen as an invited space from the GP perspective, it was a closed space as far as community or citizen participation is concerned. Successes included improved relationships and GP services as well as improved communication and systems between primary and secondary care. In an associated closed space GPs and health authority negotiated the development of a new service.

Community priorities and the NICP priorities were very different. Efforts to engage with community were prompted by this study. The need was not recognised organically nor really understood by most of the GPs. Involvement of community voice was not seen as a priority and so as a result of the lengthy time it took to organise the first meeting and the GPs disengagement from the Partnership the idea never got off the ground.

The action research project opened a new and dynamic, transient, *claimed* space to assess drug users' views of health service and attempted to influence policy. More than any, this

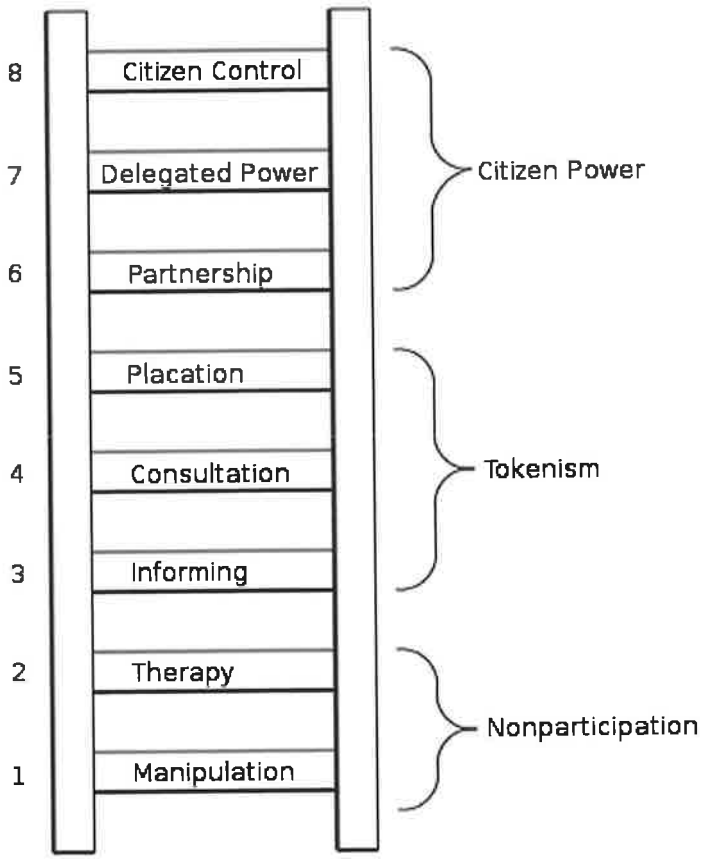
space shows the chasm between the policy rhetoric about involvement in decision making and the real experience and perceptions of those using the services.

Power relations in spaces for participation

Power relations help to shape the boundaries of spaces for involvement, define what is possible within them and determine who may enter them. Those who create the space are more likely to have power within it and those who have power in one may not in another (Gaventa 2006). Power can be transferred shared or expanded once a space is created however if the new transformed power is not legitimized it can revert to those who created the space. This is reflective of what occurred in the NICP space and contributed to its demise.

Arnstein (1969) intended the ladder of participation in figure 21 to be used for citizens, as opposed to professionals, to gain power. With the absence of community in the decision making arenas, I found the struggle in health service decision making to be between the bureaucrat and the clinician. This is reflective of a wider cultural shift in health care which sees public service managers rather than medical practitioners determine how services are organized and delivered. This follows what has been referred to as the 'new public management paradigm' (Lupton, Peckham, and Taylor 1998b;Milewa, Dowswell, and Harrison 2002)

Figure 21 Arnstein's Eight rungs on the ladder of citizen participation



Source (Arnstein 1969a)

Participation in the NICP space up until the reform of the health system (which coincided with key Partnership personnel changes) could be described as 'partnership' (rung 6 on the ladder). However when there was a conflict of interests the HSE exercised power through agenda control and deferred decision making, so that the level of participation according to Arnstein was 'Tokenism', with the HSE providing information only (rung 3).

In the development of the 'out of ours' in the closed space, service binding measures in the form of a company and contracts were established which saw the advent of a power sharing model between the health authority the GPs. Ironically it was in this closed space that conflict was more apparent and yet power sharing resulted. The emerging partnership could be

described as rung 8 on Arnstein's ladder. The GPs controlled 'North doc' a company established to provide the GPs for the' Out of Hours' run by the HSE. GPs have full control over the medical service. They agree to share (with the HSE) planning and decision-making responsibilities through such structures as joint policy boards, planning committees and mechanisms for resolving impasses. The HSE maintain their power and influence in the partnership because their financial input and provision of infrastructure is essential (Personal Comms, manager North Doc). Of course the use of Arnstein for analysing the power sharing between the GPs and the health authority is nebulous as the whole point is to measure citizen empowerment. It does however confirm a high degree of power sharing with GPs.

Staying with Arnstein and in reference to community, power has also been redistributed through service delivery by community groups, projects, and the drugs task forces. Resource centres, local drug projects, after schools projects, summer projects, are relatively autonomous in terms of day to day management.

The ICON Health Action Forum which was established in the first quarter of 2006 was a claimed or created space by the community sector. In terms of participation it only achieved rung 3 on the ladder. It engaged with the HSE but participation was tokenistic with information only being provided.

The HAF achieved its own funding and conducted a community consultation about Primary Care and a health needs assessment. These have not been utilised by the HSE.

The action research collaboration project falls under Cornwall's 'fleeting formations' space category which are aimed at 'opening up deliberation over policies or service delivery priorities' rather than decision making (Cornwall 2002). As the ladder takes as its starting point the mechanisms by which those with power share it with citizens, our 'fleeting formation', does not fit. The collaborating group consulted with the drug users, the health authority did not.

This space showed invisible power or the third dimension of power at play in which dominating ideologies are internalised to the extent that drug users accepted their place in the order of things and their identity as addict. Nevertheless as Bergschmidt (2004) found they still desired normalization. They wanted to be treated the same as everyone else.

Interests

Analysing power relations in these spaces sees the health authority as exercising power over GPs as it (the health authority) affected GPs in a manner contrary to GP's interests (Lukes 1974);

> 'A' exercises power over 'B' when 'A' affects 'B' in a manner contrary to 'B's' interests.

This analysis, without being contextualised by 'interests' risks seeing GPs as the 'underdogs', in need of more equitable power sharing. This is where, in my view, the power analysis falls short. Though it can tell us how to recognise the exercise of power and importantly how and when power is being used to suppress complaint and conflict (as was a recurring technique of the HA) it does not tell whether this is a 'good' or 'bad' use of power. Lukes suggests that the suppression of grievance is the most 'insidious use of power'. However do the ends justify the means? Is power being misused if exercised for the purpose of intelligent services planning for the most marginalised?

Power can be thought of as capacity that enables social change or sustains the status quo (Eyben, Harris, and Pettit 2006). With this in mind, when we look at interests in the areas where the health authority can be accused of non-decision making / covert decision making, we see these 'mobilisations of bias' to allow change rather than to maintain the status quo. The purpose in one case was to keep options open so that services could be 'slipped' in for drug users at a later date, and in another to roll out PCTs, without wasting resources on a partnership which was not part of the plan. In yet another it could be argued that coercion was used so that an 'out of hours' service was established for the people of north Dublin against the original wishes of the GPs who wanted to maintain the status quo.

It is possible to link public interest to the development of the 'out of hours' service, through tracing public protest regarding A/E waiting times which was followed by the Minister for Health's plan. This incorporated the development of an 'out of hours' service. Similarly the transformation plan arose out of the National Health strategies for which there was broad public consultation. The GPs interests were, on the other hand at least partly commercially driven. Their interest in maintaining NICP was unclear but resembled an act of defiance.

Luke's (1974) warns that the notion of 'interests' is an irreducibly evaluative notion. My attempt to surmise what public or community interest was, arose precisely because it was not present in the decision making spaces.

In the two claimed spaces in this study: the fleeting formation which carried drug users voice to services and the ICON Health Action Forum; we see no impetus on the part of the health authority to make the changes identified by marginal voice nor willingness to engage in a constructive way with the Health Action Forum. The HAF model followed a community development approach and resulted in a community consultation and needs assessment similar to Lifford /Castlefinn Primary Care Project. This was offered by the HSE as a model for community involvement in Primary Care. However there was an important difference between this model and the ICON HAF; it was initiate and established from within the HA (HSE and CPA 2006;Sutherland 2004).

This form of 'conventional' participation which is government sponsored and 'top down' represents a contradiction. Some conclude that successful participation is that which is not sponsored by government and that increased participation is unnecessary and unwarranted where relations between state and citizen are more cooperative (Morgan 1993b;White 2000b). However overdependence on government funding to fund and sustain spaces for participation is a fundamental undermines independence of voice and power. In fact Arnstein takes no account of level of dependence on the powerful. The top of the participation ladder sees citizens in control and managing budgets and programmes. However as long as they are reliant in the state or in this case the health authority for funding they are vulnerable. For example the NICP achieved the sixth rung yet it was dependent on the HSE to run the partnership e.g. be responsible for and control budget, staff, and agenda. The ICON Health Action Forum only achieved the third rung, because the health authority did not share power but only passed on information. Nevertheless it was not dependent on the health authority at all. The Partnership could influence decision making but was dependent on the health authority, the HAF could not influence health service decision making but was independent of the health authority.

Deconstruction and definition

In this part I use deconstruction to show the contradictions present in the community involvement ideology in the context of current framing of Primary Care in Ireland. I do this by

highlighting some of the paradoxes identified in the literature and discovered in the course of this study. Significant among these was that community's practice of community development did not appear to lead to involvement in 'health' let alone Primary Care. This led me to examine the effect of definition framing on potential for involvement. This has consequences for what might be possible in the future.

Deconstruction has its origins in philosophy and in the work of Jacques Derrida who used it to challenge some of the accepted ideas that have permeated philosophical thought since the time of Plato (Rolfe 2005). Derrida situates the paradoxical within a particular model thereby destabilizing the truth or unequivocal value of that model (Wolfreys 2007:29). The key to an understanding of deconstruction is the aporia (literally an impassable path) which Derrida denotes a logical dilemma that can neither be resolved nor worked around. A key strategy of deconstruction is to expose the aporia which exists just below the surface of all texts (Rolfe 2005).

Paradox of participation

Tracing the origins and development of participation ideologies (chapter 3) sees community development and participation arise as a strategy from professionals, strategists and even colonial powers (Hickey and Mohan 2004b).The need for the privileged position, the facilitating outsider, to raise consciousness about their own plight implies that community members lack an accurate understanding of their life conditions (Montenegro 2002;Rifkin and Draper 2000b). The World Health Organisation at Alma Ata too situates community members in need of the expert;

> They have to acquire the capacity to appraise a situation, weigh the various possibilities and estimate what their own contribution can be. While the community must be willing to learn, the health system is responsible for explaining and advising and for providing clear information about the favourable and adverse consequences of the interventions being proposed as well as their relative costs (World Health Organisation 1978)

This view was remarkably close to the Health Manager's view at the meeting to establish links between community and the NICP;

"They [community] have to be facilitated in terms of doing that needs assessment and maybe a pre requirement would be just raising the awareness giving them the information, helping them to understand the information. (General Manager, NICP community involvement sub group)"

Another contradiction is that the approach which was meant to empower can have the opposite effect (Cooke and Kothari 2001a). Higgins found that the really disempowered are unlikely to participate(Higgins 1999). This is the case with drug service users. Our experience of attempting to influence service providers by bringing drug service users 'voice' was not empowering for any of us including the drug user representatives on the team.

This study saw decision making in closed spaces situated far from the locale. The effect of the reform process which aimed to centralise and standardise an extremely fragmented system has had paradoxical effects on community voice which was previously exercised through political representation at Health Board level (Prospectus 2003).

There is contradiction too in the fact that participation through community development was heavily dependent on State funding. I found a significant aporia or 'impassable path' or in that the strong community development approach to identifying and addressing 'felt need' did not lead to involvement in health services. The community sector was however, as shown in chapter 6 involved in actions aimed at addressing the social determinants of health.

The medical model, defines illness by monitoring changes in biological or physiological signs, while in stark contrast the social model defines it from the perspective of the individual's ability to function within their society. The community groups in the north inner city focused on changing society for the betterment of people living in their communities. They did not link these explicitly to health or articulate it in health terms. They did not see medical professionals as being very relevant to what they tried to achieve and correctly understood doctors to be interested in illness. GPs showed the flip side to this interpretation, though open to exploration, they wondered what community involvement meant and how it was relevant to what they did.

Definition and framing

Similar to boundaries on a map, or 'dividing practices', lines in definitional terms around thoughts or ideas, determines at once, both what they are and what they are not. Like any

other space definitions set boundaries that simultaneously include and exclude. The Primary Care strategy in 2001 drew a line around Primary Care defining simultaneously what it was and it was not. Though the definition was broader than Primary Medical Care it emphasised *working with* community rather than *including* community. It clarified what was central in the definition and what was not. In this respect it was not as inclusive as the Primary Health Care definition.

An article by Aronowitz shows how framing mechanisms shape population health. These framing mechanisms are how individuals and groups recognise, define, name and categorise disease states ,and attribute them to a cause or set of causes. He goes on to argue (convincingly) that these framing phenomena are sometimes the very mechanisms by which social patterning of health and illness emerge (Aronowitz 2008).

Taking a similar line, the way in which health care is framed impacts on how community is involved. I have illustrated below three different conceptual frames of health care in the community (see figure 22). This shows how with a shift of perspective (broadening definition) community is seen as involved.

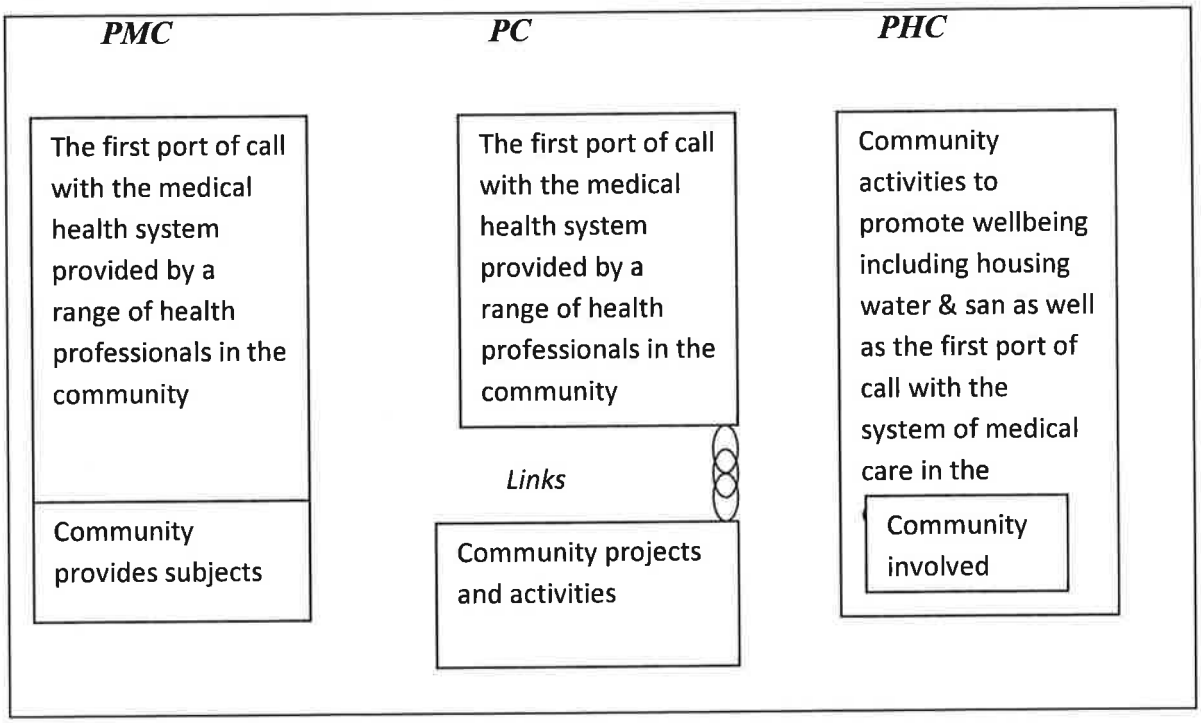
Primary Medical Care or General Practice provides medical care by primarily GPs, some with practice nurses. In this framing the community provides patients. There is no involvement of community in the collective sense and GPs are rarely involved with community agendas. Visiting the GP frames the person as a patient and the GP as expert.

Primary Care includes a range of services provided by health professionals working as multidisciplinary teams. There is an emphasis on engaging with community. Starsfield (1992) suggests that Primary Care is the compromise between PMC trying to be PHC. According to this framing, this study saw links between Primary Care and community largely through area based partnerships and health authority CDWs. The Health Action Forum and the Grangegorman working group also began to engage with the health authority towards the end of this study.

Primary Health Care (PHC) This conceptualisation is based on community involvement and cannot operate without it (WHO 1978). Primary Health Care incorporates an understanding of the social determinants of health. As such, in this study the community were very much involved in Primary Health Care using a community development approach to tackle identified

needs. This involvement included decision making in community based projects. Community groups through contract agreements with the health authority are delegated power and responsibility for service provision (after school projects, rehabilitation for drug users, drug task forces, family resources centres, youth projects etc.).

Figure 22: The implications of framing on ideas of 'involvement'



Primary care has been framed as including the work of professionals with the exclusion of community. This has placed the emphasis on team working *between* professionals and engagement with external stakeholders. Once defined in these terms the community become external and relationship is set as such.

Broadening boundaries to include

If boundaries were broadened to *include* community based efforts to tackle determinants of health then the definition of Primary Care communities would be seen as involved in Primary Care through the community work they are already doing.

Reframing Primary Care

Judgements on levels and success of community involvement in Primary Care are dependent on how Primary care is framed. This explains why many reviews and evaluations have been very positive of the community development approaches to community involvement even

though they may not have achieved actual influence on formally defining Primary Care (Crowley 2005b;HSE and CPA 2006;Sutherland 2004). Because the community development ideology is closely associated with the Primary Health Care model, both Primary Care and Primary Health Care are often interpreted as being synonymous (Bhatia and Rifkin 2010a). It also allows for a wide range of activities to be considered as involvement outside the formally defined services.

Reframing Primary Care as Primary Health Care would effectively include those groups in the community sector within an area that are providing services and funded by the health authority. It would also require a wider analysis of conditions in which poor health problems are created by the Primary Care System. This view broadens the definitional boundaries of Primary Care. This would not require a net funding change but may change how funding is administered (local rather than centrally). It would make explicit the full range of activity which exists under the health banner in an area. It would also immediately improve judgements of community involvement in areas of high community sector activity such as the north inner city and identify areas requiring support based on deprivation and low community sector activity.

Democratising decision making

If Primary Care is not reframed then policy rhetoric should take account of the actual service provision structure and set more realistic aims for the purpose and methods of 'involvement' with external stakeholders i.e. community.

The evidence suggests that there is a need to democratise decision making with in the health authority. This could be addressed by opening spaces for participation at the local level of significant decision making (LHO Manager) with agreements and protocols for governing participative mechanism e.g. Agreement with the City Council (DICP and DCC 2004). A mix of interests from a coherent community area within the LHO area should be represented. It should be recognised that extremely marginalised groups in communities are unlikely to be represented in these spaces so separate mechanisms for taking account of their views and experience is required.

The majority of drug users could be treated by GPs in Primary Care in the community rather than in special clinics, if GP would agree to provide methadone maintenance. Segregation and other 'dividing practices' contributes to the reified identity of 'drug users' and serves to

dislodge individuals who are also sons and daughters, fathers and mothers, partners and lovers, from community (Saris and O'Reilly 2010). Addressing some of the stigmatising practices present in the treatment of addiction might be more beneficial to the people they affect, than strategies aimed at involving them in *invited* spaces. These are often imbued with power differentials reflective of the society in which they are marginalised in the first place (Cornwall 2002;Gaventa 2006).

Spaces are opportunities, moments, and channels, where citizens can act to potentially affect policies, discourses, decisions and relationships that affect their lives and interests (Gaventa 2006).The concept of participation as a spatial practice is a useful frame. It allows opportunities be recognised and absence of space to be identified. With regard to local area health services, the following questions should be asked; 'In which space does this decision-making occur and who are the actors? Can such spaces be widened to include more democratic decision making? What kinds of spaces can be claimed or created to influence this kind of decision making? This spatial conceptualisation allows non democratic spaces be 'seen' and therefore targeted. It highlights where spaces are closed or when one kind of space should be transformed to another, and it helps identify risks associated with certain types of spaces. All spaces for participation are not automatically *good* and should not be entered without a risk assessment and a plan for establishing rules of engagement. Thinking spatially can help towards building strategies for more transformative social action (Cornwall 2004).

Final note

Because there is a gap between policy and practice it does not simply follow therefore that practice should be spurred on in order to catch up with policy. The fragmented health system which requires reform is at least in part a result of prioritisation of local interests which are not always in tandem with national interests. A coherent system with identifiable access to multidisciplinary Primary Care teams serving the same catchment areas is still required. Strong leadership at the local as well as the central levels is required to ensure a system of Primary Care is established based on the principles of equity, quality, and fairness. In this regard I concur with Jewkes and Murcott (1998) who state:

> Local democracy in health may be more effectively promoted if health policy makers and managers focus their attention on improving the decision making accountability,

transparency, choice, and rights of redress within existing procedures rather than pursuing what looks more like some holy grail of community control.

Reflecting on role, position and participation

As an initial outsider to the different sites, which I came to know pretty well, I spent a long time learning what was done but more importantly how things were done. Over time I began to understand what words and actions meant. As an anthropologist friend once said

" I hung around long enough to get the jokes"

While I concluded that power relations helped shape the boundaries of spaces for involvement, and defined what was possible within them, they also influenced the nature of my participation. Reflecting on my experience within different 'spaces' and indeed outside of others I find my modus of participation mirrors my findings. The roles I adopted were influenced by the power relations and the 'rules' in various social settings.

'J' was an ex heroin addict, now on methadone with an alcohol problem. In response to being asked to list the health services he used, he said "Trying like, is it?" (page 106). In his short reply 'J' suggests that for him like many others with most need there is no access without much effort. He didn't use health services- he tried to. There were invisible boundaries that could not be negotiated.

My efforts to access sites of significant health service decision making were frustrated by similar boundaries; they were hidden, elusive and only open to certain elites. In the end I did not access sites of significant health services decision making and planning. Meetings held to design a new Out of hours services were private closed affairs with senior officials and GP representatives. It took months to get the final okay to participate in the NICP meetings, where it turned out significant decisions were not being made. At the one meeting were the most significant decision in over 50 years of the Department of health (establishment of the HSE) was being shared with the NICP management and GPs, I was asked not to attend. Reflecting on my role in the spaces where I did get access , I realise that not only did I learn though what I observed of others in those settings but I also learnt by how I participated. In order to learn I had to determine what I had to do to fit in, and achieve my goals.

In as much as the researcher constructs the field she is also constructed by it. Most field research is involved somewhere between the two poles of 'complete participant' and 'complete

observer' (Hammersley and Atkinson 1983). Though my aim for all settings was to get as close as possible to the perspective of the people I was observing as unobtrusively as I could, my role was nevertheless, different in each setting. I had planned to be closer to the observer end of the observer – participant continuum in each setting. However this principle contradicted my aim to 'get to know' in some settings. As I reflect on my actions as a participant in different settings I find they accord with the structuring principles of the social groups I was getting to know.

Some views of participant observation suggest a dual role both as participant who feels, hears and sees as subjects do, and observers who remain detached and 'objectifying'. This approach assumes objective observation is possible. Savage points out that there is no clear boundary between the external and internal worlds of the researcher and that we inhabit the world through our embodied interactions (Savage 2003). I found many of the practices I consciously and subconsciously enacted such as dressing, talking and even smoking, accorded with the structuring principles of the social groups I was getting to know.

In the 'invited space' of the NICP I adopted a clear role which others could identify, if not quite understand. I did the same at all meetings; I sat at the meeting table, a little off to the side and took notes. Though this position could be construed as the 'privileged observer' (Brewer 2000) which is how I originally interpreted it, on reflection, in this setting, this role turned out to be quite participative. I was doing what others did, I fitted in, and as time went by I learned to fit in more.

Before and after meetings I engaged in 'safe' conversation without expressing views or giving opinion on anything that had been discussed. I learned to copy the clear detachment between meeting contents and 'normal life' which behaviours within this setting encouraged. This gave a sense that everything was going to plan even when it clearly wasn't (e.g. GPs were protesting and so not attending meetings). Image was important in this setting; I thought about what I would wear and tried as hard as I could to look like a professional (which usually meant wearing the same striped trousers and regretting my eyebrow ring). I helped make the tea and set up before and clean up after meetings. My actions gradually aligned me more with the health authority staff than busy GPs. Even though I did little else but observe and take notes, I was fitting in with others who did the same. In this 'role' culture environment, once my role was established, it did not matter what I did or didn't do, it was unlikely to be challenged or changed. My actions accorded with the implicit rules laid down in the setting. Though this (NICP) was a partnership between GPs and the health authority, my behaviours reflected my

(at the time subconscious) feelings that my participation in this 'invited space' was theirs, rather than the GPs, to determine. In this way my actions were influenced by the power dynamic.

The GPs behaved differently. While they were open and interested in what I was doing (research) they couldn't see how the whole community 'bit' fit with in what they were doing. They came and went from meetings in a hurry from and to their practices. Their sense of hurriedness seem to signal a sense of them as a special and more important than the health authority managers at the meetings. So I followed them to their practices where I could find out more about their actions, views and perspective. Following them from the symbol of partnership and unity between Primary Care Providers (NICP), to their individual practices which by and large were separate from health authority services (and theoretical Primary Care Team members) also reflected the broader findings of 'fragmentation' and 'isolation' in Primary Care services.

Reflecting on my participation in the community setting I see how, over time, my participation responded to patterns and rhythms in the community setting. In the community sector I didn't have to think about what I would wear or regret my eyebrow ring. In fact though I was new to this setting I became comfortable in it quite quickly. I identified with the sense of cause, purpose and desire to change things. The ease with which I settled in to this setting forced me to challenge my assumptions and interpretations more rigorously.

I found the multi-sited approach assisted in this challenge, as perspectives of one group challenged the others. In this arena I would find myself huddled outside buildings with community groups and members on coffee brakes, during meetings, forums, workshops and conferences. In this site it was acceptable to challenge and argue but not to side with anything the government had done. Besides taking up smoking again and dressing comfortably in community setting I felt I had to contribute in some way. These were the rules in this sector; everyone had to make an effort towards the goal of change. This meant I served as a steering group member for one of the projects. My work as advocate ethnographer in the 'claimed space' for drug users and participation on the Health Action forum, made me acceptable and gave me close access to perspectives and agendas within the sector. However, except for the 'claimed space' it did not compromise my overall marginal position. Unlike the NICP the dynamic breath of activity within the sector meant that not everyone had a role everywhere. Researchers in the community sector were not novel, and I was given access to anywhere I

wanted and facilitated with access to community members in their own homes and groups e.g. tenants committees.

Interestingly reflecting on my embodied participation with UISCE and drug users I find my smoking increased my dress became more casual and warmer as engagement was often outside (I usually wore the same green combat styled coat). My 'uniform' was different for the different sites to the extent that my partner could usually say where I was going and who I would be hanging out with without being told. The uniform was a 'conformiform'- it conformed to the spaces I was to occupy and to those I was meeting.

Physical infrastructure was also different in the different sites; the NICP meetings were usually in old dilapidated buildings that had a previous purpose (often associated with psychiatric institutions); community settings were wide and varied including converted churches, halls, hotels, resource centres, people flats and houses. My interactions with drug users (apart from the focus groups) were generally outside; on the steps of clinics, on street corners, along the boardwalk, and on occasion in people flats. The juxtaposition of the empty psychiatric institutions and the lack of place for the addicts never failed to make me think of the changing ways in which social structuring influences the framing of disease-years ago asylums full of 'lunatics' today streets full of 'addicts'.

At the start of this research I had been uncomfortable about ambiguity surrounding the proposed dual role as researcher and as change agent (community development worker). I was concerned that how I observed things would be influenced by my position. Eventually however I became a change agent of sorts in the 'claimed space' to further drug user's views to improve services.

I felt the community development ideology was being imposed by PC who wanted to prove it worked. As such it was coming from the wrong side (according to community development principles, and mine) of the power divide, i.e. Primary Care provider rather than community. This paralleled the paradox I was finding in theory. However I also had other considerations regarding my positionality which were eventually satisfied by the mix of roles and range of settings. Through my participation, I both experienced and observed the disconnect between community groups and Primary Care, particularly in general practice. In the community 'associational spaces', Primary Care was poorly represented, likewise in the NICP; community was not represented. Drug users, in contrast to their better experience in the community, were

very poorly represented in both NICP and Primary Car. The action research position allowed me to become a participant. Because I continued to engage in the other sites, gaining a multiplicity of perspective, I felt I could afford to risk 'over rapport' in one site. The position as part of the group trying to influence services allowed me learn through lived experience what it was like to be associated with the marginal view and encounter at first hand the barriers to change. My impressions were influenced by my position as participant, while trying to influence the services as a researcher. Both my colleagues and I in spite of our positions and professions, felt like outsiders at times and often felt disempowered and demoralised. This experience helped me understand the sense of non-participation of those who are most marginalised.

This project would probably not have progressed as far as it did if I had not taken an advocate role. I noted a number of times that the next meeting of the group would not have happened had I not organised it and that preparing the reports and presentations was largely my doing. As such, it is not presented as model for change that does not rely on particular skills and personalities. Rather it is presented as a form of participative practice that with given circumstances, and personalities, may hold possibilities to effect social change.

It is also presented as an example of the difficulties inherent in endeavouring to change systems established to maintain the status quo. Community development fails to recognise that personalities are important in levering open chinks to widen spaces for involvement in decision making models. However I also feel the aim to detach the outcomes from the personalities, who in many cases are more responsible for them than the approach, risks the misuse of power in the name of an ideology such as community development / participation.

My roles as participant, advocate, and researcher gave me the opportunity for understanding from these different perspectives. If power can be thought of as the capacity that enables social change or sustains the status quo I experienced power as Foucault describes as flowing and circulating and changing through different spaces at different times. At different times in different places and spaces I found myself positioning myself next to each group in respect of power dynamics both physically and in terms of role. Through reflecting on my positioning and my own reaction to power dynamics I learned about my assumptions about power as well as about power relation in the various settings. The extra dimension of understanding that underpinned my confidence in that understanding was informed by these experiences within the sites themselves.

Epilogue

September 2011

The economic recession hit as my field work finished. Plans for Primary Care Centres in both the northeast and northwest of the inner city were shelved. Many staff took redundancy packages offered by the HSE. Those who had begun engagement with the NWICN and the ICON Health Action Forum left or moved to other areas. There is no engagement currently. The ICON Health Action Forum has written to replacement managers but efforts received a "stony silence".

Primary Care Teams have been constructed on paper by the health authority. GP are 'associated' with particular health authority services. This means 'teams' have meetings. They do not necessarily share the same case load of work from the same buildings. Some doctors go to meeting others do not depending on the number of 'teams' they are associated with. There is no attempt to involve community.

The NICP has remained closed. The Out of Hours service continues to provide a much needed service. Hundreds of drug users continue receive methadone maintenance in the stand alone drug treatment clinic.

Step by step as funds dried up so did state funded community development. Agencies such as the Combat Poverty Agency which had previously enjoyed a distance from the state were subsumed into government departments. In 2009 the Combat Poverty Agency was integrated with the Office for Social Inclusion within the Department of Social and Family Affairs. In 2010 the Social Inclusion Division became part of the Department of Community, Equality and Gaeltacht Affairs. From May 2011 the division moved to the Department of Social Protection.

Six years after the planned development of a new Primary Care Centre on the Mountain View Court site .. it remains an empty space.

Photo: S Rubbathan Sept 2011

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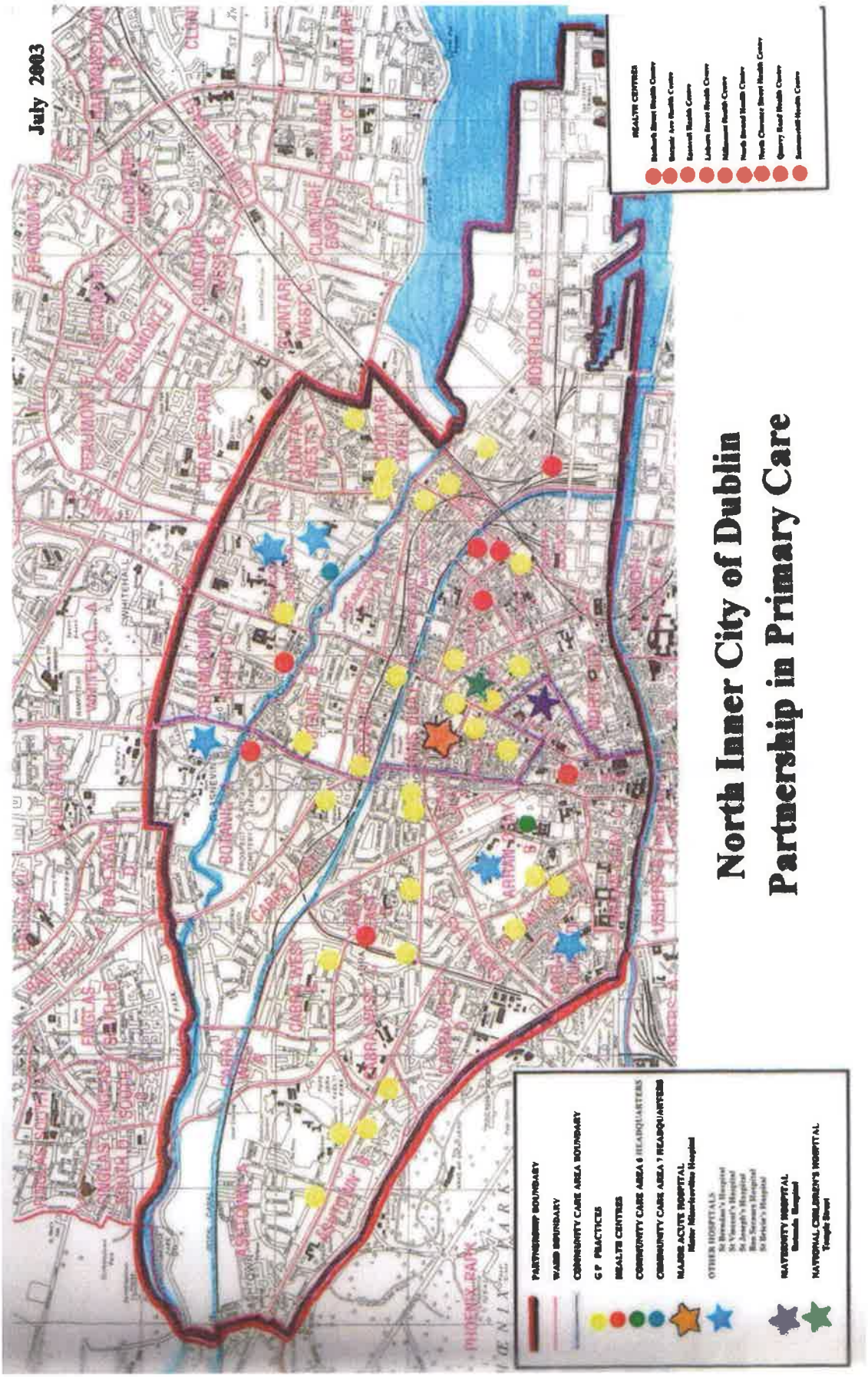
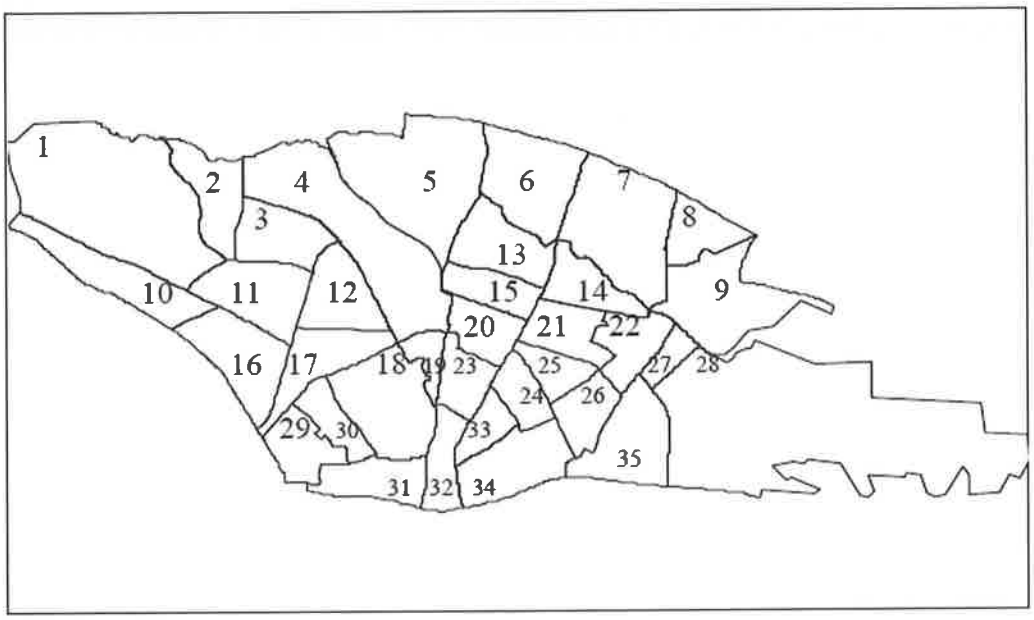

July 2003
North Inner City of Dublin
Partnership in Primary Care

Purpose of the focus group discussion
The information collected in this focus group will be used with other information collected to:
1. Gain an understanding of view of health service
2. Advocate for appropriate health care for drug users

Question Type	Question
Introductory Question	Tell us your name and how long you've been using drugs.
Transition Question	*ER, mark on the list how many of the group have experiences of the different services and ask if there are others (e.g. clinics in hostels) that participants have experience.*
Key Questions	Are there any of the above services that you have felt you needed but could not get? -If yes which ones? -Why?
	Have you got a medical card? - If no why? - If yes, how did you find the process of getting a medical card (what did you have to do, how easy or difficult was it)?
	(*systematically take each of the other services and ask the following question for each, starting with the one which most people have experience of first)* What is your impression of this (say which) service?
	What is good about the service (say which)?
	What is bad about the service (say which)?
	How did/ does using the service make you feel?
	Did you ever make a complaint about the service? - If yes were you listened to and what happened - If no why not
	Have you health problems that are not looked after by the listed services? - What are they?
Ending questions	If you had the chance to give advice to the managers of the service (say which), what would you say?
	We wanted you to help us to see what is lacking in health care for people with a drug problem. We also wanted you to help us see if your rights are being upheld? Is there anything we have missed?

North Inner City Partnership in Primary Care (NICP) Electoral Divisions (EDs)

1	Ashtown A	19	Arran Quay A
2	Cabra A	20	Inns Quay A
3	Cabra West B	21	BallyboughB
4	Cabra East A	22	BallyboughA
5	Botanic A	23	Inns Quay B
6	Drumcondra South C	24	Rotunda A
7	Drumcondra South A	25	Mountjoy B
8	Clontarf West E	26	Mountjoy A
9	Clontarf West D	27	North dock A
10	Ashtown B	28	North Dock B
11	Cabra West C	29	Arran Quay D
12	Cabra East B	30	Arran Quay E
13	Botanic B	31	Arran Quay C
14	Drumcondra South B	32	Inns Quay C
15	Botanic C	33	Rotunda B
16	Cabra West D	34	North City
17	Cabra East C	35	North Dock C
18	Arran Quay B		



NWIC & NEIC EDs	Pop 02	% >65	% <15 years	% renting from local authority	Nat. Deprivation index[1]	Unemployment rate[2]	% education stopped at 15 yrs[3]
ARRAN QUAY A	1390		10	10	9	10	14
ARRAN QUAY B	3089	6	9	6	10	11	12
ARRAN QUAY C	2,375	5	6	8	10	11	11
ARRAN QUAY D	3,675	10			10	17	29
ARRAN QUAY E	2,902		11	11	10	14	23
INNS QUAY A	3,373		6	6	10	21	20
INNS QUAY B	2,935		12	19	10	14	20
INNS QUAY C	2,359	10	16		10	18	24
Total NWIC	*22,116*	*12*	*11*				
BALLYBOUGH A -	3,368	13		34	10		
BALLYBOUGH B -	3,009	9	14	11	10	21	21
Drumcondra South B	1,377		12	9	9	6	34
MOUNTJOY A	3,242	7			10		22
MOUNTJOY B -	2,725	7	13	13	10	24	18
NORTH CITY	3,942	4	4	9	10	8	6
NORTH DOCK A	1,287	13	13	2	10	11	22
NORTH DOCK B	3,628			6	9	13	30
NORTH DOCK C	3,568	4	15		10	16	20
ROTUNDA A -	4,199	5	16	22	10	19	15
ROTUNDA B -	1,752	6	14		10	17	15
Highlighted		*>13%*	*>16%*	*=>20%*		=>20%	=>25%
Total NEIC	*32,097*	*8*	*15*				
Total	54213	10	13				
Dublin city	495781	13	16				
State	3917203	11	21			14%	

[1] An index based on CSO Small area population statistics at Electoral division level: unemployment low social class local authority housing car availability and over crowding. '1' denotes a relatively affluent area while '10' denotes the most deprived areas.

[2] Those either looking for first regular job or unemployed having lost of given up previous job as a proportion of the total labour force.

[3] People 15+ whose full time education has ceased. Census of Population 2002Small Area Statistics for DICP catchment area. Produced Jan 2004 DICP

NWIC & NEIC EDs	Deaths (SMRS) 94-98[4]	% with Medical Card	Number on CTL	%>15s on CTL per 1000 pop[5]	All site cancer SIR[6]	Persons with a disability[7]	Number of highlighted indicators
ARRAN QUAY A	119.3		11	9	1.13	8	2
ARRAN QUAY B	138.8***	26	32	11	1.29*		3
ARRAN QUAY C	156.1***	25	39	18	1.60*	6	2
ARRAN QUAY D	147.0***		77	26	1.26*	9	
ARRAN QUAY E	126.2***		45	17	1.13	2	3
INNS QUAY A	77.6**	13	13	4	0.50*	13	3
INNS QUAY B	127.2**	28	56	21	1.05	12	3
INNS QUAY C	174.1***		54	27	1.38*	10	
Total NEIC			327				
BALLYBOUGH A	166.2***		103	40	1.50*	11	
BALLYBOUGH B	154.2***		33	13	1.25*	10	4
- Drumcondra south B	119.3	28	6	5	1.18		3
MOUNTJOY A	190.2***		164	63	1.31*		
MOUNTJOY B	159.2***		73	31	0.97	7	4
NORTH CITY	100.9	12	45	12	1.33*	5	1
NORTH DOCK A	124.1	24	7	6	1.18		1
NORTH DOCK B	133.9***		20	7	1.21*	11	
NORTH DOCK C	172.7***	27	89	29	1.05	7	3
ROTUNDA A	185.9***	24	69	20	1.24	7	3
ROTUNDA B	166.0***	26	37	25	1.39	10	3
Total NWIC			646				
Highlighted	*>130* **	*>30%*		*=>20/1000*	*=>1.30*[+]	*>10%*	>5

[4] Health Information Unit, HSE: Health Intelligence and Population Health 2005

[5] Numbers registered on Central Treatment List (CTL) during 2004 as proportion of population over 15yrs.

[6] All invasive cancers 1994-2001, excluding non melanoma skin cancer. Expected cases based on estimated 1999 ED/ward populations (interpolated from 1996 and 2002 SAPS). ERHA REFERENCE Source National Cancer Registry

[7] Census of Population 2002 Small Area Statistics for DICP catchment area January 2004. DICP

Who is doing what in the community?

Organisation type	North east inner city organisations
Network	ICON The employment network African women's network Irish Nat Org of the Unemployed
Community Dev/support	CAN Community Tech Aid Tosach Community media network Vincentian partnership for social justice
Employment/ Edu/training	Doelbusters Job Centre Fire Station Artists studio Inner city enterprise Inner City Renewal Group Larkin Unemployment Local employment centre Mountjoy women's edu unit NCCCAP North Wall CTW North Wall women's centre Parents education group Dublin Adult learning centre Youth reach &Youth reach transition
Drugs	Citywide drugs crisis campaign ICON drugs support Talbot Centre Crinin Youth Pro.
Support for recovery/rehab	Ana Liffey Drug project ACRG SAOL Soilse
HIV/Aids	Cairde Dublin Aids Allience
Children &Young people	Adventure Sports Project After Sch Ed and Support Ballybough Youth Project Belvadere Football club Comm after sch Pro Lourdes youth and comm. Nickol Project Sherrif st youth club St Vincents Trust St Agatha's Youth Development Project East wall play group North Wall youth developments group
Children and family/parent support	Curam Family Centre NYP1 NYP2 Parent support Hill Street Family Resource Centre
Crèche & Pre school	St Bridget's Day Nursery

	Abbey day nursery Little learners crèche Sheriff street pre school St Bridgids day nursery
Community resource centre	Ballybough Lourdes Community RC Lourdes parish centre
Homeless	Child Care Centre Dublin Simon Community
Disabilities	Forum for people with disabilities Nat assoc for the deaf IntroArt
Tenants/res Ass.	Avondale tenants association Champion avenue tenants Croke Villa's Tenants Fitzgibbon street tenants Dominic street tenants Georges st. tenants Glouster street tenants Gardner street tenants Hardwicke street tenants Hill street tenants James Larkin tenants Killarney avenue tenants Liberty house tenants Lourdes house tenants Mc Dermott apt tenants North Clarence st. tenants North William st. tenants O'Brien Hall tenants Sean Tracey house tenants Sheridan court tenants Mary's Mansions tenants
Advise and info	Centre Care Treoir
Elderly	Lourdes Day Care
Travellers	Pavee Point
Refugee	Irish Refugee council Reception and Integration agency
Culture &Arts /sports	African Cultural Project

Compiled as part of mapping in 'initial phase'.

Community Representation in a Primary Care Team – Lifford/Clonleigh Resource Centre:

The context of this project was one of 10 Department of Health and Children supported national pilot Primary Care Teams in which there was a requirement to show community participation. Two places on the team were allocated to community representatives. The health authority approached the Lifford/ Clonleigh Resource Centre to begin the process.
A community participation working group comprising membership from the community development project, the Primary Care Team and the health services was established.
Focus groups were conducted with community groups and members to establish needs and a local Community Health Forum was established.
The Forum supported three community representatives on the Primary Care Team and identified a number of priorities for the community representatives to feed into the Primary Care Team. They included issues that directly affected the health service alongside non-medical priorities such as the need for support groups, benefits advice, childcare support and environmental issues. It was reported that many positive developments had taken place in the area, most of which have been spearheaded by the Community Health Forum. There were reported improved relationships between community and professionals, GPs and nurses. It was noted that the community, however, continues to be concerned about on-going funds for the participation process.
(see A model for Community Participation in Primary Care. Lifford Castlefinn, Primary Care Project.2004. DoHC, CPA HSE)

Health Needs in Isolated Communities – Meitheal Forbartha na Gaeltachta/Comhar Dhuibhne (MFG) is an established organisation with strong community ties, led on developing links between the Primary Care Team and the local communities. The process was started with a community needs assessment to establish a baseline to identify health needs and engage marginalised people in the Primary Care Project Planning Team. At time of review it was hoped to improve local access to health planning. MFG acknowledged some apathy amongst the community regarding the possibility of achieving change. Among the Primary Care Team, there was reluctance to raising expectations regarding what could be changed. There was a sense that the Primary Care Team was struggling to get organised and was concerned that it was not sufficiently coherent to engage with the local community. The members of the Primary Care Team were new to each other and in some cases had never spoken to each other.

Source: *Community Participation and Primary Care: Learning from the Building Healthy Communities Programme.* (Crowley 2005b)

Linking Social Development, Health and Physical Regeneration – Fatima

Groups United: Fatima Groups United is a representative group of residents and community groups who work to ensure that social regeneration is integral to the overall regeneration of Fatima Mansions in Dublin. It aimed to develop of a community health and well-being centre in the area in partnership with at least one of the local general practices also aimed to influence the regeneration process. This project faced consultation fatigue among the local population. The area had been the subject of many community consultations in the past, making it more difficult to inspire participation. The community wanted centre to focus on alternative therapies, health education, a baby clinic, citizen's advice and other services. The local GPs have engaged well with the community representatives. A community development and health training course has been developed to build the capacity of the local community to actively participate in accessing Primary Care, at time of review twenty local people are attending this training.

Primary Health Care Group Mulhuddart – Greater Blanchardstown Development Project

The context for this project was an already established Primary Health Care Group comprising statutory and community groups who were lobbying for a Primary Health Care facility in the deprived area of Mulhuddart. The Building Healthy Community programme funding was used to produce an analysis of the health problems and possible obstacles to addressing them. The report also set out a clear strategy for the community to pursue in trying to influence decision making at all relevant levels of the health service. This proved useful as a guide for future community action and brought together data that could be used in making the case for health resources in the area.

A stronger community voice developed to make demands for resources. An extensive needs assessment was conducted and community health activists were identified. A direct political lobbying approach was used at govern Department of Health and Children and Health Service Executive (HSE) levels. At time of review a pharmacy had been established in the area, and there was increased public health nursing a community welfare officer and speech and language therapy service have been established. Three new GPs and a dentist were setting up in the area and a site has been identified for a Primary Care centre.

Source: *Community Participation and Primary Care: Learning from the Building Healthy Communities Programme.*(Crowley 2005b)

Policy document	Relevance to community involvement in Primary Care
Shaping a healthier future: a strategy for effective healthcare in the 1990's (Department of Health 1994b).	The first comprehensive healthcare strategy in Ireland, launched in 1994, emphasised the importance of ensuring the views of public and patients were taken into account
Quality and Fairness A Health System for you. Health Strategy(Department of Health and Children 2001c)	The Strategy encourages participation of people in decision-making at all levels; 'The health system must become more people-centred with the interests of the public, patients and clients being given greater prominence and influence in decision-making at all levels.' Action 52 'Provision will be made for the participation of the community in decisions about the delivery of health and personal social services.'
Primary Care A New Direction. Quality and Fairness - A Health System for You, Health Strategy.(Department of Health and Children 2001a)	The strategy gives a clear commitment to involving communities in decision making and implementation. 'Community participation in Primary Care will be strengthened by encouraging and facilitating the involvement of local community and voluntary groups in the planning and delivery of Primary Health Care services' It goes on to state that communities must be enabled to, 'Become actively and genuinely involved in defining the issues of concern to them in contributing to the decision making in respect of the planning development and delivery of services and in the monitoring and evaluation arrangement' Action 19 of the strategy states that 'Mechanisms for active community involvement in Primary Care teams will be established'. Elsewhere in the document the role of the community is described in terms of being i)service provider; 'involving formal service agreements and referral protocols', ii)representation 'direct membership on Primary Care management teams', and iii)service users with whom 'meaningful dialogue which allows the views of the community to be heard and taken into account'. The strategy says that Primary Care services will be based on an assessment of local need. It sees participation of community groups as essential in the needs assessment and in the design and delivery of appropriate local services
Guidelines for Community Involvement in Health (HeBE 2002).	The definition of Community Participation is suggestive of the community development ethos 'A process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing

	and delivering services and in taking action to achieve change' There is acknowledgement for the need to move from consultation to involvement in determining priorities, assessing needs and decision making. community development is seen as central to this movement. Specific guidance is given under the four deliverables under action 52 of the strategy: Informing and educating the Public, the establishment of regional advisory / co-ordinating committee and randomly selected consumer panels as well as a National Consultative Forum (HeBE 2002).
Guidelines for community involvement in health. Position paper of the National Primary Care Steering Group.(Deane 2004b).	It is evident from the resultant report that community involvement was taken as *'a good thing'* and not as requiring further justification. It was also evident that community involvement was being defined in accordance with community development ideals and principles; 'firstly a community development approach is needed to develop peoples capacity to facilitate and enable their participation in projects, this leads to effective community involvement/engagement'
Framework to guide development of Primary Care teams and Primary Care networks(Department of Health and Children 2004).	The framework document sees Primary Care as the provision of 'comprehensive, effective, efficient and equitable services in local communities, capable of dealing with all but the most complex medical conditions '. This means it says that Primary Care will be capable of coping with 90-95% of all health and personal social service requirements. The principles underpinning community involvement are that - PCTs ensure user participation, including involving local community and voluntary groups in service planning, delivery, monitoring and evaluation. - Communities must have an input to local needs assessments initiated by the statutory health agency. - The ability and capacity of communities to determine the services they require needs to be acknowledged. - Community Involvement should be seen as an ongoing process. It stipulates that the process of communication and engagement between providers and the community should start at the planning stage of PCT establishment of Primary Care Teams and Primary Care Networks.
Health Act: Number 42 of 2004	Part 8 of the Health Act (2004) that established the HSE and dissolved the Boards mandated the HSE as follows: 'To establish mechanisms for involving public representatives, users of health and personal social services and other members of the public in matters relating to those services' Section 8 of the 2004 Health Bill allows the Executive 'take steps to consult with local communities or other groups about health and personal social services as it considers appropriate'. These may take the form of advisory panels whose terms of reference and governing rules would be the responsibility of the Executive
Corporate Plan 2005-2008 (Health	HSE Corporate Plan 2005-08 (Objective 4) that states

Services Executive 2005)	'We will develop the HSE as a dynamic, effective and learning organisation in partnership with service users, patients, staff, not-for profit/Voluntary/Community Sector and other stakeholders. This means that we are committed to listening to and learning from the experience of our service users, partner service providers, staff and other stakeholders. We will actively consult around the planning, delivery and evaluation of our services'
(Department of Health and Children and HSE 2008).	The strategy describes three levels of engagement: - Individual service users: involvement in their own care - Community: involvement in local service delivery and development - National: strategic policy informed through involvement of service user organisations in partnership with health care professionals. Involvement is defined as per HeBe 2002 quoted above. The Principles in the strategy move beyond seeing 'involvement' at the 'consultation' end of the spectrum to specifying involvement in the development of services and in own care. They specify the socially excluded groups who must be engaged and evaluation of all service user involvement initiatives. The Strategy document specifies measurable action points for each of seven goals under the following themes; • Commitment and leadership • A systematic approach o effective service user involvement • Patient involvement in their own care • A Patients charter • Involvement of Children young people and socially excluded groups • Development of existing structures In terms of Primary Care the specific deliverable itemised is 'the increased involvement of service users in Primary Care teams'

Original

Sharing control: user involvement in general practice based methadone maintenance

Fiona O'Reilly, David O'Connell, Austin O'Carroll, David L Whitford, Jean Long

Ir J Psych Med 2011; 28(3): 129-133

Abstract

Objectives: This study assessed patients' views of a methadone programme in a Dublin general practice including the degree to which the patients were 'involved in decisions about their treatment'.

Method: All patients receiving methadone were asked to participate. A face to face questionnaire, with open and closed questions, was administered. Interviews lasted approximately 30 minutes. Quantitative data were analysed using descriptive statistics and qualitative data were analysed using a thematic approach.

Results: Forty one (87%) of the 47 patients attending the general practice methadone service were interviewed. Of the 39 patients who had used heroin on admission, 69% had stopped and 31% reduced heroin use since starting methadone treatment. A total of 71% reported that the doctor either always involved (59%) or sometimes involved (12%) them in decisions about their treatment. Involvement was interpreted as 'being listened to' or 'having a say' in deciding methadone dose. Surprisingly those who reported that they were not involved in treatment decisions were more likely to have stopped heroin use (10/11). A significant majority of patients (81%) expressed the desire to stop taking methadone.

Conclusion: Most patients receiving methadone in general practice were listened to and had a say in deciding their methadone dose but did not have an opportunity to engage in more structured or contractual forms of involvement in treatment such as written care plans. In line with a patient centred approach, treatment providers should set their sights beyond the safe delivery of methadone, to provide a service which is centred on patient goals, expectations and choice.

Key words: Consumer participation; Methadone; Primary health care; General Practice.

***Fiona O'Reilly**, Independent Research Consultant, Donabate, Co Dublin, Ireland. Email: Fiona.A.OReilly@nuim.ie
David O'Connell, GP trainee, North City Dublin GP Training Scheme, Eccles St, Dublin 7, **Austin O'Carroll**, General Practitioner, Mountjoy St Family Practice, 53 Mountjoy Street, Dublin 7, **David L Whitford**, Professor of Family & Community Medicine, RCSI-Medical University of Bahrain, **Jean Long**, Head of Unit, Alcohol and Drug Research Unit, Health Research Board, Third Floor, Knockmaun House, 42-47 Lower Mount Street, Dublin 2, Ireland.
*Correspondence

SUBMITTED: APRIL 6, 2009. ACCEPTED: SEPTEMBER 21, 2010.

Introduction

After decades of research, the effectiveness of methadone maintenance treatment in reducing heroin use and associated problems including involvement in crime and reduced transmission of blood-borne viruses is well established.[1,2] In Ireland legislative and administrative regulations to control the prescribing and dispensing of methadone have been in place since 1998.[3,4] Their purpose is to prevent the diversion of methadone onto the black market and reduce the risk of overdose deaths.

Regulations include registering each person who is prescribed methadone and restricting prescribing and dispensing to doctors and pharmacists who have undergone special training. Protocol regulations include restrictions on the number of patients a doctor and a pharmacist can prescribe and dispense to.

During treatment a patient's consumption of methadone is supervised either on a daily or weekly basis depending on the patient's level of non-prescribed drug use, which is assessed by means of urine testing. In Ireland one-third of patients on methadone maintenance therapy (MMT) attend a general practice for their treatment.[7]

As part of the general healthcare system, patients are encouraged to actively participate in decisions about their own treatment, as well as to provide input into policy decisions about the treatment service itself.[8] Though patient involvement is a characteristic of modern health systems it is not well supported in the context of addiction services.[9,10]

Our study explores patient involvement in treatment decisions and their views of the methadone programme.

Method

The study setting was a sizeable general practice in a deprived area of Dublin. Patients treated for heroin addiction were seen, separate to other patients, at one of two set times each week by one of two general practitioners. The practice manager attended the 'clinic' and general assistants were available to observe patients providing urine samples. This is common practice in drug treatment clinics and aims to ensure the sample the patient is providing is their own sample. Nursing and counselling services were available by appointment.

The study population included all patients in receipt of methadone treatment at the general practice. The interviewer administered questionnaire was developed in collaboration with the general practitioners and the drug user's forum, (Union for Improved Services Communication and Education, UISCE).

Interviews were conducted over a four week period during July and August 2006. Data on demographics, client history with the service, views of different aspects of the service, involvement in decisions about treatment, health status and

drug use were collected. The questionnaire included open and closed questions and took approximately 30 minutes to administer. Answers to closed questions were coded and analysed using descriptive statistics. Bi-variate analysis was conducted using Fisher's exact tests. Answers to open questions were recorded verbatim. Quantitative and qualitative data were entered into SPSS 14. Some qualitative data were used to explain or expand on closed questions. All qualitative data were coded through eye balling and labelling individual units of meaning. These codes were then re-categorised according to emerging themes. Quotes illustrative of specific themes were selected for inclusion in this paper.

Service users attending the methadone services verified the analytical interpretation of the data.

Results

Forty-one (87%) of the 47 patients attending methadone treatment at the general practice were interviewed. One patient refused to participate, one was in prison, two were not in contact with the service during the study period and two did not attend the interview.

Demographics

At the time of the study, the patients' ages ranged from 21 to 53 years with a mean age of 34.5 years. Over one-third (37%) were 36 years and older. Patients were predominantly male (73%) unemployed (54%) and single (63%). A significant minority (44%) lived in private rental accommodation and over one-fifth (22%) lived with family members. Four patients (10%) lived in hostels.

Client history with the service

At the time of the study, 60% attended the service for over four years and 24% attended for less than one year. Most patients (95%) attended the service once per week. Patients were referred from a wide range of services with the largest single proportion (46%) being referred from drug treatment clinics.

Changes in drug use

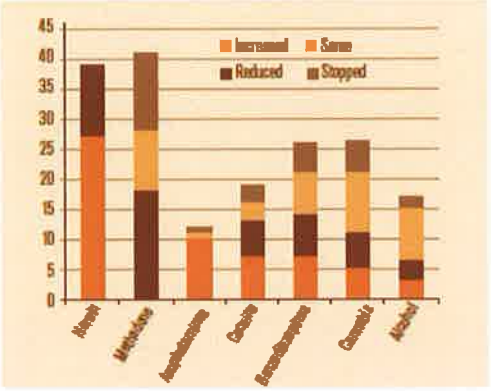
Thirty-nine patients had been using heroin on admission to the practice. Of these, 69% had stopped using heroin and 31% reduced their heroin use. Nine of the 10 patients using amphetamines had also stopped. The numbers who had stopped or reduced their intake were relatively small *(see Figure 1)*. A number of patients reported continued use of heroin (12), amphetamines (1), cocaine (12), benzodiazepines (19), cannabis (21) and alcohol (14).

Involvement

A total of 71% said that the doctor either always involved (59%) or sometimes involved (12%) them in decisions about their treatment. Forty four per cent reported having an agreed plan with their doctor regarding 'where their treatment was going'. The remainder stated they did not have an agreed plan (51%) or did not know if they had one (5%). The majority of those with a treatment plan described it as 'verbal in nature' (78%) and subject to review.

A total of 61% stated that their doctor decided the amount of methadone they were prescribed while 34% stated that

Figure 1: Reported changes in drug use since starting with the service



the doctor and client jointly decided the dose. Just under 50% said that they had a say in deciding the prescribed dose although some said this decision was within limits:

- *"I do have a say; but it's more up to the doctor" (Participant 21)*

Others felt their experience was being taken into account by the doctor;

- *"He'll ask me how I'm feeling, sleeping, eating, how things are going, he listens" (Participant 19)*
- *"You say it isn't holding you and you need extra" (Participant 41)*

Those who felt that they did not have a say (36%) commented that the decision-making power was with the doctor:

- *"He has the power... You take what's given" (Participant 20)*
- *"It looks like a partnership but at the end of the day the doctor decides. When they decide on your dose, that's it" (Participant 30)*

A total of 44% of responders said they would like to be more involved in decisions regarding their treatment. Improved dialogue was cited as the most appropriate means to greater involvement though some suggested group meetings may be helpful.

Table 1 presents a comparison between those who said they were involved in decisions about their treatment and those who said they were not involved. Those who said they felt involved in decisions about their treatment were more likely to feel the service was helping them, to have a treatment plan, and to have a say in deciding the dose of methadone. They were less likely to be stable in terms of illicit opiate use, to be in the service for more than a year and to want more involvement.

As lodging a complaint is one way for service users to influence service provision, patients were asked how they would go about making a complaint if they had one. Of the 35 who answered this question, 40% would go to a member of staff (usually the doctor), 26% said they would not make a complaint (as nothing would be done or it may be held against them), and 11% would go to the service users' forum or to the health authority.

Almost one-quarter (23%) did not know how to make a complaint. Just over one-third (34%) made comments suggesting a lack of confidence in an internal complaints system.

- *"If I had a complaint I don't think I would make it.. the doctors are going to back the receptionists and vice-versa. They are not going to go against each other for an addict" (Participant 31).*

Patient's goals

Patients were asked about their long-term treatment goals. A total of 17% expressed a desire to continue methadone treatment into the future but the majority of patients stated that their long term goal was to stop taking methadone, either in the immediate future (59%) or eventually (22%).

Views of 'the service'

Of the patients 83% stated that the service was helping them to achieve their goals with three themes emerging: stabilisation, motivation and referral

i) Patients described the stabilising effect of being on methadone as making it possible to lead a normal life:
- *"If I wasn't getting methadone I'd have to smoke everyday... it stabilizes you so you can go back to work" (Participant 41)*
- *"It keeps you away from the street and other elements and to spend more time with the family... and if you want you can hold down a job" (Participant 36)*

ii) Some felt that the service providers motivated them to come off drugs:
- *"I would have been on heroin if I wasn't here. It does push you now and again... Since I'm getting stable now I'll start to come off soon" (Participant 39)*
- *"It pushes you, but sometimes I'm not ready" (Participant 1)*

iii) Others appreciated referral to other services, eg. counselling and inpatient detoxification:
- *"(It's helping me) by letting me see the counsellor... she passed me on to other people who are giving me support" (Participant 3)*
- *" (names doctor) is putting me down to go into treatment" (Participant 37)*

A minority felt the service was not helping them to reach their long-term goal:
- *"...it's the same thing every week. Throwing a mouthful of phy down me isn't going to help me" (Participant 31)*
- *"All I see is a doctor for five minutes here – I get all the other support I need at (names another service) from counsellors and in one to one sessions. It's daily support you get there" (Participant 15)*

While the majority felt the methadone service helped them to achieve long-term goals, they also identified other substantial requirements in order to recover from addiction. The most common requirements were a stable environment (away from temptation) and a sense of purpose (something to do each day).
- *"Get somewhere to go... to get away from everyone and then have somewhere safe to come out to" (Participant 25)*
- *"Permanent accommodation, not hanging around the streets all the time, getting a job and having take-aways.*

Table 1: Comparison of patients on the basis of feeling involved in treatment decisions

	Feels involved in treatment decisions (%)	Does not feel involved in treatment decisions (%)	p value (Fisher's exact test)
N	26	10	
Life more involvement (13)	3 (12)	10 (91)	<0.001*
Outlined treatment plan (17)	15 (63)	2 (18)	0.022*
Services helps (28)	22 (92)	6 (55)	0.021*
Say in dose prescribed (20)	19 (79)	1 (9)	<0.001*
Doctor decides dose (11)	1 (38)	10 (91)	0.004*
Not using heroin (25)	15 (63)	10 (91)	0.112
Attending more than 1 year (25)	14 (58.3)	11 (100%)	<0.02*

*Statistically significant results $p < 0.05$

When you have a job you're occupied and kept away from it" (Participant 19)

Supervised urine testing

Most (83%) felt that supervised urine testing (providing a urine sample under observation) was necessary and accepted it as part of the rules which must be adhered to when receiving methadone treatment. Among those who said it was necessary, there were those who indicated that they had 'no problem' with this practice (53%) and those who expressed they had some level of discomfort (41%) about it either in the past or currently.

Accepted urine testing without reservation:
- *"It's no problem. Its part of it" (Participant 12)*
- *"If it has to be done it has to be done. It's alright. I've no problem with it." (Participant 21)*

Accepted urine testing with some reservation:
- *"I don't mind but it's degrading" (Participant 10)*
- *"I feel a bit paranoid about it" (Participant 23).*

Another six per cent thought the practice was necessary but did so against their feelings of discomfort;
- *"I'm not comfortable with someone looking at me" (Participant 2)*
- *"I don't like it full stop. It's degrading" (Participant 7)*

Daily supervision of methadone consumption

A total of 61% felt that daily supervision of methadone consumption (drinking methadone in the pharmacy every day under observation), usually as a consequence of opiate positive urines, helped reduce their use of heroin. Amongst these there existed the view that it was either 'necessary' or 'fair', with several commenting that it served as an aid to abstinence:
- *"I think it's fair. You need some sort of consequences" (Participant 16)*
- *"That's the right thing to do because if I hadn't been thrown*

off or supervised (daily) I would still be using" (Participant 39)

- *"Because it makes me think twice about using with the trouble of going to the chemist everyday" (Participant 37)*
- *"It's right... I'm on dailies since last year but it's my own fault" (Participant 35)*

A total of 34% felt that being put on daily supervision of methadone consumption did not act as a deterrent to heroin use and some suggested it may be counter productive because it increased exposure to illicit drug use:

- *"I think it helps you meet more people where drugs are available and it can be tempting" (Participant 13)*
- *It frustrates more than anything else. You just say f*ck and go and use... rebel against the punishment (Participant 17)*

Dissatisfaction was expressed regarding the practical inconvenience that it caused;

- *"It's ridiculous when you have three kids! You have to drag them all with you" (Participant 4)*
- *"If they're living local it's one thing, but for me living in (names area outside Dublin) it's really unfair" (Participant 14)*

Positive and negative attributes of the service

Thirty-three patients described what they considered as positive aspects of the services while 28 described negative aspects. Positive comments related to the service 'helping' and being 'good and fair'. They described the staff as being friendly and competent, particularly the doctors: Listening and understanding were appreciated attributes as well as 'respect' they were shown.

A total of 28 people described some negative aspects which described a service that was not user friendly in terms of timing of clinics and having to leave children outside. Negative comments relating to treatment of the person included examples of lack of trust and respect by some staff.

Discussion

The meaning of patient involvement remains ambiguous in the literature. It has been conceptualised broadly as patient-centeredness which relates to doctors adopting the biopsychosocial model in preference to a purely biological model along with a more equal rather than paternalistic doctor-patient relationship.[11-13] More focused interpretations concentrate on shared decision making with clinicians, health literacy and self-management of chronic conditions.[14] In our study respondents appeared to interpret involvement as having good dialogue, feeling they were being listened to and having a say in deciding their methadone dose. While good dialogue and being listened to may be precursors to involvement they do not necessarily imply it. Having a say in dosage implies a more equal relationship, though as some patients observed the power ultimately lies with the doctor.

It is good news that all patients had ceased or reduced illicit opiate use and that there was a high level of satisfaction expressed by service users who alluded to the presence of support from caring staff. However, high consumer satisfaction levels in drug or alcohol services are not a good predictor of service performance.[15-17] Some authors suggest that this is because drug and alcohol service users often perceive themselves as undeserving and have low expectations.[15,16] While some studies suggest a link between satisfaction levels with patient involvement in care planning,[18] others found that even where this is below standard from a programme perspective there continues to be a high level of satisfaction.[19] This echoes our finding of appreciative service users though none had involvement in formal care plans.

The poor link between satisfaction levels and programme characteristics means that patient views, though an important aspect of service evaluation, should not be taken as the definitive statement about the value of service provision.[18-20]

The comparison of those feeling 'involved' with those who did not feel in any way involved suggests an association between feeling uninvolved and being stable. Nearly all of those who did not feel involved said they were no longer using heroin. It is plausible that the sense of non involvement of those who are stabilised relates to the interpretation of involvement as centring on 'deciding the methadone dose'. Once stability is reached and the dose is set this involvement ceases. In fact, it was the view of the GP that there was little to be involved in once stability on methadone was achieved.

While 'stability' on methadone may be an end point and a marker of success from the service providers' point of view, this study suggests that service users do not share this perspective. Most, wanted to be drug free and did not want to be maintained indefinitely on methadone. Similarly, McKegeny found that though patients aspired towards abstinence they ended up maintained on methadone maintenance for years.[21,22] As such, drug service users' goals are more in line with an abstinence approach rather than the harm reduction model, which long-term maintenance supports. Though retention in treatment is reinforced by a strong evidence base, particularly in respect of social outcomes, it may not be in keeping with consumer choice.[9,23]

While there have been calls for the provision of user based choice and participation in shaping goals,[10,23] some authors suggest this is less straight forward in the context of addiction services; that 'partnership with patients' reduces the ability to 'counter manipulations' by them.[9] While the treatment of heroin addiction has been likened to the treatment of people with chronic illness[24-26] some regulations are based on an assumption that service users can not be trusted (patients observed urinating to ensure they cannot provide false samples and observed drinking methadone to ensure they do not sell it). Can shared decision making and other markers of patient involvement in treatment decisions exist where such regulations are considered necessary?

The fact that a majority of patients in our study accepted these measures as necessary may suggest that they can. The acceptance of these rules may indicate that such a regime provides a reasonable incentive for patients to 'stay clean' and a disincentive to sell methadone on the black market. Bergschmidt provides another interpretation however, positing that patients may accept these checks due to a belief fostered by the system, that they had 'lost their entitlement to social existence'. Thus, due to a 'desire for normalisation' they accepted controls that would be unacceptable in other chronic medical conditions.[27] The difference between what patients find acceptable and what they find helpful can only really be assessed in the context of patient choice.

Our study highlights a gap between what patients said they wanted (abstinence) and what they were experiencing (maintenance). Reasons for this gap require further exploration.

One possible explanation is the lack of adequate facilities, particularly residential and rehabilitative, to support the achievement of abstinence for those with this aim.[30] Another possible explanation which McKegeny offers for similar findings, is that the desire to become drug free is a long-term and ultimate objective, while maintenance may be more in line with an intermediate aim.[31] A third explanation is that the patient's view of an appropriate treatment path conflicts with the doctor's view which may be more influential in treatment decisions.[30,31] Whatever the reason for the gap between aspirations and experience, it is likely to be less extreme in the context of real choices made by patients.

Conclusion

Most patients receiving methadone in general practice were listened to and had a say in deciding their methadone dose but did not have an opportunity to engage in more structured or contractual forms of involvement in treatment such as written care plans.

Patients who have become stabilised and who wish to eventually stop taking methadone do not feel involved in their treatment; this may be due to disharmony between the patients' long-term aim (to be drug free) and the aim of methadone treatment 'to reduce or end heroin use and the harm associated with it'.

In line with a patient centred approach, treatment providers should set their sights beyond the safe delivery of medicine, in this case methadone, in order to provide a service which is centred on the patient goals and expectations. This undoubtedly requires a range of treatment options to be made available to patients and service providers including further training for GPs. Involvement in treatment decisions and care is likely to build patient confidence and their sense of responsibility for the management of their care. At the very least it is likely to narrow the gap between expressed goals and treatment goals. Patient choice on type of treatment experienced and how this is delivered should be made more explicit in the treatment of opiate addiction in Ireland.

Declaration of interest: None.

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